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Patient-driven innovations reported in peer-reviewed journals: a scoping review

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ABSTRACT

Background Awareness of patients' innovative capabilities is increasing, but there is limited knowledge regarding the extent and nature of patient-driven innovations in the peer-reviewed literature.

Objectives The objective of the review was to answer the question: what is the nature and extent of patient-driven innovations published in peer-reviewed scientific journals?

Eligibility criteria We used a broad definition of innovation to allow for a comprehensive review of different types of innovations and a narrow definition of 'patient driven' to focus on the role of patients and/or family caregivers. The search was limited to years 2008–2020.

Sources of evidence Four electronic databases (Medline (Ovid), Web of Science Core Collection, PsycINFO (Ovid) and Cinahl (Ebsco)) were searched in December 2020 for publications describing patient-driven innovations and complemented with snowball strategies.

Charting methods Data from the included articles were extracted and categorised inductively.

Results A total of 96 articles on 20 patient-driven innovations were included. The number of publications increased over time, with 69% of the articles published between 2016 and 2020. Author affiliations were exclusively in high income countries with 56% of first authors in North America and 36% in European countries. Among the 20 innovations reported, 'Do-It-Yourself Artificial Pancreas System' and the online health network 'PatientsLikeMe', were the subject of half of the articles.

Conclusions Peer-reviewed publications on patient-driven innovations are increasing and we see an important opportunity for researchers and clinicians to support patient innovators' research while being mindful of taking over the work of the innovators themselves.

Strengths and limitations of this study

- ► To our knowledge, this study is the first attempt to perform a comprehensive review of what has been published in peer-reviewed journals about patient-driven innovations.
- ► The review had a systematic approach in searching four large databases, complemented with snowball sampling.
- ► Patient-driven innovations are not always labelled in the research as patient-driven innovations and as such, despite the methods used including snowball sampling, the result is likely an under-representation of research of patient driven innovations.
- ► The study contributes to concepts and operational definitions related to patient innovations, pointing out the result of using an inclusive and broad definition of innovation and a narrow definition of what is meant by patient driven.

BACKGROUND

Traditionally, patients have been considered as passive recipients of medical care, merely 'buying' and consuming the services and products that experts (eg, researchers, healthcare professionals, 'medical producers') have created.[1] However, healthcare providers are increasingly regarding patients as experts in their own conditions, involving them and their family caregivers as active participants in care.[2–4] Although most policies promote a more active patient role in care, research has found that in reality, patients' role remains limited.[5 6] Patients repeatedly report having too little influence over their care while their needs remain unmet in the current healthcare systems.[7 8]

Many patients want to play a greater role in decisions about their care, to perform more effective self-care, and to engage in improving healthcare systems.[3 4] For example, patient innovators take part in the development and spread of patient-driven innovations.[9–11] The Patient Innovation website (www.patient-innovation.com), which was created to collect innovations by patients and/or family caregivers, lists over 1200 innovations. This gives an indication of significant activity by patients and their family caregivers driving health innovations, often independently of the health system. Patient innovators have been defined as 'patients or their nonprofessional caregivers (eg, parents and family members), who modify or develop a treatment, a

technical aid product, or a medical device to cope with a health condition'.[7] Although the awareness of patients' innovation capacity is increasing, there is still limited knowledge regarding the extent and nature of patient-driven innovations in the peer-reviewed literature.[7 12] In the discussion section of this paper, we consider possible explanations for this. The objective of the review was to answer the following research question: What is the nature and extent of patient-driven innovations published in peer-reviewed scientific journals?

METHOD

Design

A scoping review method was chosen as the most appropriate for the objective of the study because our initial investigations revealed a diverse range of types of studies and publications, and the method is recommended as useful when examining emerging areas of research.[13] It was performed according to the five-stage framework proposed by Arksey and O'Malley[13] and is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA) Checklist[14] (online supplemental appendix 1). Critical appraisals of articles were not performed since the aim was to explore the extent and nature of patient-driven innovations, not assess the quality of these. The review does not follow a preregistered protocol.

Definition of key concepts

To find a shared understanding of the concept 'patient-driven innovation', the research team performed a concept analysis inspired by Walker and Avant.[15] The concept analysis was performed in a collaborative workshop with patient innovators and researchers where we used key articles to identify model cases of patient-driven innovation, and borderline cases, related cases and contrary cases. Using the concept analysis method, the team agreed to define 'innovation' based on the WHO definition of health innovation as 'an innovation that identifies new or improved health policies, systems, products and technologies, or services and delivery methods that improve people's health and well-being. The innovation aims to add value in the form of improved efficiency, effectiveness, quality, sustainability, safety and/or affordability. The innovation can be preventive, promotive, curative, rehabilitative, assistive and/or palliative care.' The other part of the concept was 'patient driven' that we agreed consisted of two parts and was defined by: (1) The innovation is user driven, meaning that it is both initiated and driven (in development, implementation, etc) by patients and/or family caregivers and (2) The innovation responds to one or more unmet needs of the innovator. Unmet needs are defined by the innovator. This provided a definition broad enough to allow for a comprehensive review of the nature of patient-driven innovations but limited 'patient driven' to focus on the role of patients and/or family caregivers (see table 1).

Eligibility criteria

Eligibility criteria are presented in table 1. We included studies published in peer-reviewed journals (publication years 2008–2020) that covered health innovations initiated and driven by patients and/or family caregivers (hereafter referred to as patient-driven innovations, as defined in table 1, point 4.1–4.3.). Review articles were used to identify original articles, and review articles that

Table 1 Eligibility criteria for inclusion

Inclusion criteria	Exclusion criteria
1. English language	Other language than English
2. Published between January 2008 and December 2020	Published earlier than 2008 or later than 2020
3. Published in a peer-reviewed journal	Not published in peer-review journal
4. Reporting on patient-driven innovation(s) as defined by three criteria: 4.1. Based on WHO's definition of health innovations the innovation identifies new or improved health policies, systems, products and technologies, or services and delivery methods that improve people's health and well-being. The innovation aims to add value in the form of improved efficiency, effectiveness, quality, sustainability, safety and/or affordability. The innovation can be preventive, promotive, curative, rehabilitative, assistive and/or palliative care. 4.2. The innovation is user driven, meaning that it is both initiated and driven (in development, implementation, etc) by patients and/or family caregivers. 4.3. The innovation responds to one or more unmet needs of the innovator. Unmet needs are defined by the innovator.	Article is out of scope (context other than healthcare) No innovation described Described innovation is not patient-driven
5. The innovation is the focus of the article	The innovation is used for data collection but not described in the article

presented original data not presented elsewhere were included. We limited the review to reports and publications made from the year 2008 and onwards because our initial searches found few reports or publications about patient innovations before 2008. Articles where the innovation (primarily the online platform PatientsLikeMe) was used solely for data collection were excluded.

Information sources

Four electronic databases were searched in October 2019 and the search was updated in December 2020: Medline (Ovid), Web of Science Core Collection, PsycINFO (Ovid) and Cinahl (Ebsco). We also employed snowball sampling: (1) The webpage www.patient-innovation.com was screened for names of innovators and innovations and those names were used to search records in PubMed (January 2020); (2) Reference lists of included articles were screened (August 2020) and (3) Names of identified patient innovators were used for author search in Web of Knowledge (August 2020).

Search

Key articles on patient-driven innovations were used by MR to form a search strategy in consultation with librarians at the Karolinska Institutet University Library. The search strategy was tested and refined three times to ensure that all key articles were identified. A complete search strategy for Web of Science is presented in table 2 and for all databases (Medline (Ovid), Web of Science Core Collection, PsycINFO (Ovid) and Cinahl (Ebsco) in online supplemental appendix 2.

Selection of sources of evidence

Records were screened by six authors (MR, AB, HJ, SR, HH and CW) and two research assistants (see the Acknowledgements section) in the open-source software Rayyan,[16] according to eligibility criteria. To screen the large number of records identified at this stage, we first collected and applied the selection criteria to titles and abstracts of the papers discovered in the search. When

Table 2 Search strategy used in MEDLIN

Interface: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily Date of Search: 15 October 2019 Number of hits: 3443 Comment: In Ovid, two or more words are automatically searched as phrases; that is, no quotation marks are needed

Field labels ·
- exp/=exploded MeSH term
- /=non exploded MeSH term
- ti,ab,kf.=title, abstract and author keywords
- adjx=within x words, regardless of order

*=truncation of word for alternate endings

#	Searches	Results
1	((adult child* or patient* or caregiver* or caregiver* or carer* or family or husband* or "next of kin*" or partner* or spouse* or user or wife or wives) adj1 (directed or driven or driving or initiated)).ti,ab,kf.	4150
2	(co creat* or co design* or collaborative creation* or collaborativ* created or "do it yourself" or "doing it for themselves" or diy or e patient* or lead patient* or participatory design* or public driven or superuser*).ti,ab,kf.	3444
3	Patient participation/	24568
4	or/1–3	31910
5	Equipment design/	144620
6	Inventions/	1720
7	Organisational innovation/	23978
8	Diffusion of Innovation/	17239
9	(innovat* or invention* or invented).ti,ab,kf.	128952
10	Self-Management/	1492
11	exp Self-Help Devices/	11126
12	exp Self care/	52825
13	(assistive technolog* or co care or self care or self help device* or self management* or self monitor* or self track*).ti,ab,kf.	42096
14	or/5–13	388764
15	4 and 14	3235
16	(co innovat* or patient* innovat* or patient design*).ti,ab,kf.	219
17	15 or 16	3443

abstracts were not available, we retrieved the full paper to decide if the selection criteria were met or not met to carry forward to the next stage of the review.

Screening was blinded and a minimum of two researchers conducted the screening for each article. Inclusion/exclusion decisions were compared. In 7% of the cases, researchers disagreed about inclusion/exclusion, and these conflicts were resolved by consensus through discussion among authors based on a full-text screening.

Data charting process and data items

A template for data charting in Microsoft Excel 2013 was developed iteratively by all authors, who worked in pairs to extract data. Extractions were compared within the pairs by those who extracted the data and merged by MR.

The final extraction form included items on the characteristics of the studies (journal, publication year, first author country of affiliation, publication type, study aim, study design, data and sample size), and on the innovations (name of innovation, name of innovator(s), description of innovation, unmet needs that the innovations aimed to fulfil, and medical condition). Extracted data is published in online supplemental appendix 3.1–3.3.

Analysis of review findings

MR performed an initial overview of the extracted data and proposed preliminary categories for each data item. PM, CW, CS, HH, AB and HJ worked in pairs with sorting the data according to suggested categories and refined the categories and suggested additional categories when needed. Detailed description of the categorisation of data ispresented in online supplemental appendix 4.

Patient and public involvement

This study was performed within the auspices of the cocreated research programme 'Patients in the driver's seat! A multimethod partnership programme on patient-driven innovations', where patient innovators are engaged as equal partners in research. The research programme members were engaged in the research meetings and contributed to the research questions, definition of patient-driven innovations and selection of sources of evidence (see the Acknowledgements section). Furthermore, SR, a patient researcher[17] living with Parkinson's disease, coauthored the current paper and was involved in all stages of the process.

FINDINGS

The systematic search generated 7220 records after duplicates were removed; the snowball sampling generated 559 additional records. In total, 7629 records were screened by title and abstract and 414 records were screened in full text for eligibility. Of these, 96 articles on 20 patient-driven innovations were included. The study selection process is reported in a PRISMA flow diagram (figure 1).

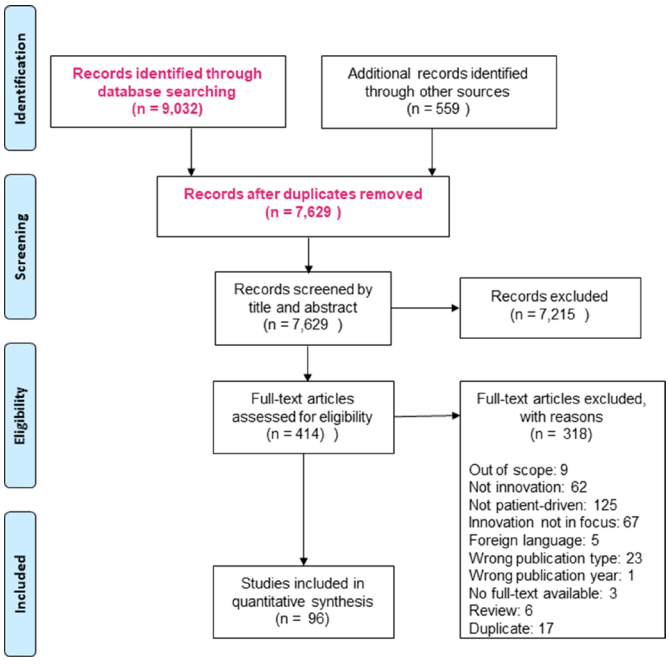

Figure 1 PRISMA 2009 flow diagram. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

The nature of patient-driven innovations

The 20 identified innovations addressed the unmet needs of patients and family caregivers with diabetes (7 innovations, 46 publications[18–63]); cancer (1 innovation, 1 publication[64]); rare diseases (3 innovations, 5 publications[65–69]); gastrointestinal diseases (2 innovations, 4 publications[70–73]); disabilities (2 innovations, 3 publications[74–76]); Parkinson's disease (2 innovations, 3 publications[77–79]) and mental illness (1 innovation, 2 publications[80 81]). There were also innovations targeting unmet needs of multiple conditions (2 innovations, 32 publications[82–113]). Data by innovation are presented in table 3.

Many of the innovations involved digital technologies, with four mobile apps, four collaborative networks, five technical innovations for diabetes care and one sensor that measures output volume from one's ostomy. Other innovations included one jacket with pockets for postoperative drain tubes, one pen-and-paper form for personalised medical records, a painted staircase (optical illusion) to prevent gait freezing, and ingestion of pig-worms to improve symptoms from Crohn's disease. Among the 20 innovations reported, the Do-It-Yourself Artificial Pancreas System (DIYAPS) and PatientsLikeMe.com, an online health-related social network, accounted for half of the articles.

Extent of publications

Author affiliations were exclusively in high income countries with 56% of first authors with affiliations in North America, followed by 36% from European countries (see table 4). One first author had their affiliation in Asia and six in Oceania. The number of publications increased in later years, with 69% of articles published 2016–2020

Table 3 Innovation-specific information

Medical condition	Innovation	N articles	Innovator(s) mentioned in the article(s)	Type of innovation	Innovator(s) listed as author
Cancer (breast cancer)	Jacki Jacket	1	Cathy McGrath	Patient clothing	No
Diabetes	Autosens	1	Dana Lewis, Scott Leibrand	Technical innovation for diabetes care	Yes
	Autotune	1	Dana Lewis, Scott Leibrand	Technical innovation for diabetes care	Yes
	DIYAPS, Do-It-Yourself Artificial Pancreas System	21	#wearenotwaiting-community, Dana Lewis, Adrien Tappe, Bastian Hauck, Tebbe Ubbe, Saskia Wolf, Timothy Omer	Technical innovation for diabetes care	Yes
	MySugr	2	Fredrick DeBong	Mobile app	Yes
	Nightscout (CGM in the cloud)	3	#Nightscout movement, specific innovators not reported	Technical innovation for diabetes care	Yes
	Omnipod	2	John Brooks III	Technical innovation for diabetes care	Yes
	T1resources.uk	1	Mike Kendall	Online network	Yes
	Webdia	1	Jean-Luc Mando	Mobile app	Yes
Disabilities	Upsee	2	Debby Elnatan	Wearable devise	No
	(No name) Auditory stimulation	1	Debby Elnatan	Auditory stimulation	Yes, last author
Gastrointestinal diseases	Ostom-i-Alert	3	Michael Seres	Technical	Single author or not author
	(No name) Helminth therapy	1	Sean Ahrens	Alternative treatment	Single author
Mental illness	No name (self-tracking number of hallucinations)	2	Spencer Roux	Technical innovation for self-tracking	Yes
Multiple	PatientsLikeMe	29	Jamie Heywood, Benjamin Heywood, Jeff Cole	Online network	Yes in some
	Medistory	1	Olive O'Connor	pen and paper medical journal	Yes
Parkinson's disease	No name (A painted staircase)	2	Mileha Soneji	Paint on floor, optical illusion	Yes
	No name (a smartphone app for collecting data on drug intake and well-being)	1	Sara Riggare	Mobile app	Yes
Rare diseases (22q11 deletion syndrome)	(No name) patient driven collaborative initiative	1	Anne Lawlor	Collaborative network	Yes
Rare diseases (cystic fibrosis (CF))	Upstream dream, Genia	2	Andreas Hager	Mobile app	Yes
	Sweden CF Coalition	2	Andreas Hager	Collaborative network	Yes

DIYAPS, Do-It-Yourself Artificial Pancreas System.

Table 4 General characteristics of studies

	N studies (%)
Continent (first author affiliation)	
Europe	35 (36)
North America	54 (56)
South America	0
Asia	1 (1)
Oceania	4 (6)
Africa	0
Publication year	
2008	3 (3)
2009	2 (2)
2010	3 (3)
2011	4 (4)
2012	2 (2)
2013	2 (2)
2014	5 (5)
2015	6 (6)
2016	10 (10)
2017	10 (10)
2018	15 (16)
2019	19 (20)
2020	15 (16)
Type of journal	
General medicine	20 (21)
Specialised medicine	51 (53)
Process related	14 (14)
Digital health	10 (10)
Patient oriented health	1 (4)
Publication type	
Original research	34 (35)
Short report	2 (2)
Protocol	2 (2)
Review (presenting original results)	6 (6)
Letter to editor/commentary	25 (26)
Conference abstract	17 (18)
Editorial	7 (7)
Special section dedicated to patients	3 (3)
Study aim	
Describe the innovation and/or development of innovation	23 (24)
Describe users and/or how users perceive the innovation	21 (22)
Test effect/impact of innovations	23 (24)
Describe/discuss ethical issues and/or policy change	8 (8)
Test feasibility of innovation	2 (2)
Aim not presented/not relevant	19 (18)
Study design	
Descriptive	42 (44)
Observational	11 (11)
Experimental	8 (8)
Design not presented/not relevant	35 (36)
Sample size	
1	8 (8)
2–100	21 (21)
101–500	9 (9)
501–1000	2 (2)
>1000	11 (11)
Sample size not presented/not relevant	45 (47)

(figure 2). A majority (65%) of the studies were published in journals with a scope of general or specialised medicine, with some in journals focused on research or healthcare processes (12%), or journals focused on digital health (10%). One article was published in a journal focused on patients' health. About half of the studies were classified as peer-reviewed research with 38% original articles, 2% short reports, 2% protocols and 6% reviews that published original results. Remaining articles were published in a peer-reviewed journal but in formats that commonly are not peer-reviewed: 24% Letters to the editor/commentaries, 18% published conference abstracts, 6% editorials and 3% in special sections dedicated to patients. Patient innovators mentioned in articles were listed as authors in most, but not all, publications. The articles seldom described the patient innovator's role in the research process.

Aims and design of included articles

Almost half of the studies (47%) used a descriptive design, while smaller proportions used an observational design (15%) or experimental design (9%) and 29% of the articles were categorised as not having a study design, for

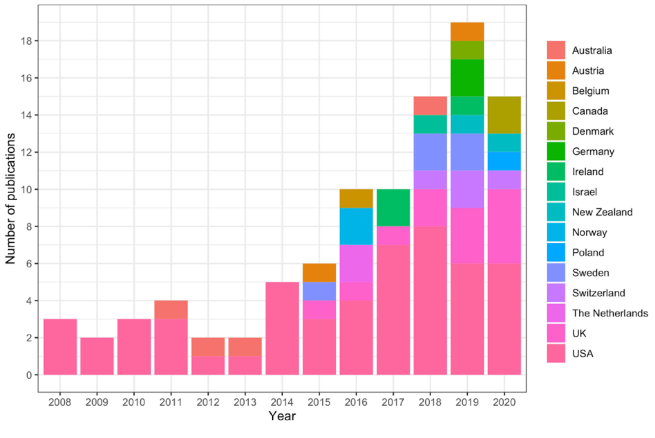

Figure 2 Number of publications per year.

example, editorials. Sample sizes ranged from one participant (8% of studies) to over 1000 participants (14% of studies). Of the 96 articles included, 77% presented a study aim, and approximately one-third of these had a study aim that focused on describing or testing the innovation: 24% aimed to describe the innovation and/or the development of the innovation, 24% to test the effect and/or impact of the innovation and 2% to test the feasibility of the innovation. Other articles aimed to describe characteristics of users of the innovation and/or describe how users perceived the innovation (22%). A small proportion of the articles described and discussed ethical issues and/or or policy changes relating to patient-driven innovations (8%).

DISCUSSION

This article reports a scoping review of publications about patient-driven innovations in peer-reviewed journals. The review identified 96 articles published from year 2008 to 2020, reporting 20 different patient-driven innovations and the number of publications increased in the later years. Among the 20 innovations reported, 'DIYAPS' and the online health network 'PatientsLikeMe' accounted for half of the articles. Considering that over 1200 patient-driven innovations are listed on www.patient-innovation.com, the number of 20 patient-driven innovations published in peer-reviewed journals is remarkably small.

Canhao *et al*[9] point out that the lack of patients scaling up and spreading their innovations to others may be an example of market failure. Based on the potential benefits of patient-driven innovations, actors such as medical product and service producers and government regulators could support patient innovators in the development and diffusion of their innovations.[114] We suggest that the lack of patient-driven innovations reported in peer-reviewed journals may also be seen as an academic failure as scientific peer-reviewed journals are important arenas for disseminating, evaluating, improving and discussing ideas in healthcare. The research community has an important part to play in complementing other ways of support for the creative contributions of the patients by using the systematic methods of research to evaluate, develop, and integrate these solutions into patients' daily lives and healthcare systems. According to Canhao *et al*,[9] there are several barriers for patient innovators that prevent them from sharing their innovations, including lack of resources, skills or access to the process of approval and commercialisation. In this review, only a minor portion of the studies had an observational or experimental design, and it is possible that similar barriers that prevent patient innovators from sharing their innovations apply to research and scientific writing.

Strengths and limitations

The strengths of the study include the broad scope of the review. We followed the process outlined in Arksey and O'Malley[13] and the review was guided by a predetermined strategy for data collection and analysis. Methodological strengths lie in this systematic approach to searching the four large databases, complemented by snowball sampling. Earlier research has reviewed specific patient-driven innovations, for example, a review of 'DIYAPS' by Kesavadev *et al*,[115] or investigated characteristics of patient innovators.[7] This is the first review undertaken of patient-driven innovations, according to a broad and comprehensive definition, and one of the very few undertaken of innovations in which patients have played a significant role in development of the innovation. This builds on Oliveira *et al*'s definition of patient innovations where innovation is limited to 'a treatment, a technical aid product, or a medical device'.[7] We cocreated a broader definition together with patient innovators in order to include social innovations such as collaborative or social networks. Thus, this broader scope and definition of patient-driven innovations was able to capture more innovations in which patients have played a significant role in the development.

The limitations of the study include the choice to only select peer-reviewed articles, but this was motivated by our aim to explore the proliferation of patient-driven innovations within the scientific literature. If the purpose had been to create an inventory of patient-driven innovations, the inclusion of grey literature would have yielded more results. Furthermore, the source of information was restricted to the included articles and in some cases the webpage wwwpatient-innovationcom. Patient-driven innovations are not always labelled as such in the publications. Therefore, despite the broader definition and the use of snowball sampling and online searches to identify the drivers of innovations, our results are likely an under-representation of research on patient-driven innovations. Also, as patient-driven innovations may initially go through commercialisation processes with a shift of 'drivers', it is possible that we would relabel some innovations as not being patient driven if we had access to more information.

Unanswered questions and future research

As this field of research is relatively new, there are several unanswered questions for future research. Considering the potential benefits that patient-driven innovations can have if they become widely used, it will be important to understand factors that may facilitate or hinder implementation, spread and scale-up of patient-driven innovations; none of the included articles in this review systematically examined these questions. It may also be important to gain deeper understanding of patient-driven innovations in general, what unmet user need they address, how they are used and by whom and what outcomes they have for patients and healthcare systems. A further unanswered question is what determines whether patient innovators decide to publish their results and if so, in which journal(s). Patient innovators were often listed as coauthors in publications related to their innovations, there was a broad variation in type of publication, and it was common

for patient innovators to coauthor articles together with established researchers and/or clinicians. Some patient innovators presented their innovations in single authored papers and others were not listed as authors. A suggestion for future studies is to interview or survey patient innovators who publish in peer-reviewed journals and explore how their reasoning around research collaboration and publishing.

This review was restricted to innovations, and we acknowledge that we, in the study selection, have excluded studies published by patient researchers if the studies were not related to patient-driven innovations. For further research we suggest a review of literature published by patient researchers and citizen scientists in general.

CONCLUSIONS

Peer-reviewed publications on patient-driven innovations are increasing and peer-reviewed journals constitute an arena where patient-driven innovations can be evaluated, discussed and developed further. We see an important opportunity for researchers and clinicians to support patient innovators' research and publication while being mindful about not taking over the work of the innovators themselves.

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Contributors MR, AB, JØ, SR, CS, CW and HH conceived and planned the review and defined central concepts; MR designed the search strategy in collaboration with Magdalena Svanberg & Emma-Lotta Säätelä at the Karolinska Institutet University Library. MR, AB, HJ, SR, HH and CW identified relevant studies; MR, AB, HJ, SR, HH, CW, CS, JØ charted the data; MR, AB, HJ, SR, HH, CW, CS, JØ collated and summarized results; MR, PM and HH drafted the first version of the paper. CW generated figure 1. HH was responsible for the overall content as the guarantor. All authors revised orrevised or critically reviewed the paper and read and approved the final draft.

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Data availability statement All data relevant to the study are included in the article or uploaded as online supplemental information. Online Supplemental files with the complete search strategy, extracted data by article and an explanation of how extracted data was categorised is available in online supplemental appendices 1–4.

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Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Title page
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4 and Table 1
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	4
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4 and Table 1
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	5
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Table 2 and Appendix 2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4, Table 2
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	6
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	6
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	6, Appendix 3

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SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Appendix 4, PRISMA flow chart
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	7-9, Appendix 1.1-1.3
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	7-9, Appendix 1.1-1.3
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	7-9, Appendix '1
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	10
Limitations	20	Discuss the limitations of the scoping review process.	10
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	13
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Title page

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

1. Medline

Interface: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily Date of Search: 15 October 2019 Number of hits: 3,443 Comment: In Ovid, two or more words are automatically searched as phrases; i.e. no quotation marks are needed	Field labels • exp/ = exploded MeSH term • / = non exploded MeSH term • .ti,ab,kf. = title, abstract and author keywords • adjx = within x words, regardless of order • * = truncation of word for alternate endings

#	Searches	Results
1	((adult child* or patient* or care giver* or caregiver* or carer* or family or husband* or "next of kin*" or partner* or spouse* or user or wife or wives) adj1 (directed or driven or driving or initiated)).ti,ab,kf.	4150
2	(co creat* or co design* or collaborative creation* or collaborativ* created or "do it yourself" or "doing it for themselves" or diy or e patient* or lead patient* or participatory design* or public driven or superuser*).ti,ab,kf.	3444
3	Patient participation/	24568
4	or/1-3	31910
5	Equipment design/	144620
6	Inventions/	1720
7	Organizational innovation/	23978
8	Diffusion of Innovation/	17239
9	(innovat* or invention* or invented).ti,ab,kf.	128952
10	Self-Management/	1492
11	exp Self-Help Devices/	11126
12	exp Self care/	52825
13	(assistive technolog* or co care or self care or self help device* or self management* or self monitor* or self track*).ti,ab,kf.	42096
14	or/5-13	388764
15	4 and 14	3235
16	(co innovat* or patient* innovat* or patient design*).ti,ab,kf.	219
17	15 or 16	3443

Reinius M, *et al. BMJ Open* 2022; 12:e053735. doi: 10.1136/bmjopen-2021-053735

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2. Web of Science Core Collection

Interface: Clarivate Analytics Date of Search: 15 October 2019 Number of hits: 1,486	Field labels • TS/Topic = title, abstract, author keywords and Keywords Plus • NEAR/x = within x words, regardless of order • * = truncation of word for alternate endings Note: sometimes “quotation marks” are needed for single search terms to avoid automatic term mapping (lemmatization).

# 11	1,486	#10 AND #9
# 10	11,179,378	TS=(disabilit* or disorder* or disease* or health* or medical* or medicine* or patient* or psychiatr*)
# 9	4,684	#8 OR #7
# 8	428	TS=(("co innovat*" or "patient* innovat*" or "patient design*"))
# 7	4,301	#6 AND #3
# 6	554,001	#5 OR #4
# 5	56,965	TOPIC: (("assistive technolog*" or "co care" or "self care" or "self help device*" or "self management*" or "self monitor*" or "self track*"))
# 4	498,702	TOPIC: ((innovat* or invention* or invented))
# 3	42,438	#2 OR #1
# 2	20,170	TS=(("co creat*" or "co design*" or "collaborative creation*" or "collaborativ* created" or "do it yourself" or "doing it for themselves" or diy or "e patient*" or "lead patient*" or "participatory design*" or "public driven" or superuser*))
# 1	22,369	TOPIC: ((("adult child*" or patient* or "care giver*" or caregiver* or carer* or family or husband* or "next of kin*" or partner* or spouse* or user or wife or wives) NEAR/1 (directed or driven or driving or initiated)))

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3. Psycinfo

Interface: Ovid Date of Search: 15 October 2019 Number of hits: 760 Comment: In Ovid, two or more words are automatically searched as phrases; i.e. no quotation marks are needed	Field labels • exp/ = exploded controlled term • / = non exploded controlled term • .ti,ab,id. = title, abstract and author keywords • adjx = within x words, regardless of order • * = truncation of word for alternate endings

#	Searches	Results
1	exp client participation/	2032
2	((adult child* or patient* or care giver* or caregiver* or carer* or family or husband* or "next of kin*" or partner* or spouse* or user or wife or wives) adj1 (directed or driven or driving or initiated)).ti,ab,id.	1154
3	(co creat* or co design* or collaborative creation* or collaborativ* created or "do it yourself" or "doing it for themselves" or diy or e patient* or lead patient* or participatory design* or public driven or superuser*).ti,ab,id.	3267
4	or/1-3	6414
5	innovation/	12769
6	exp product design/	5606
7	(innovat* or invention* or invented).ti,ab,id.	62414
8	or/5-7	67742
9	exp self-management/	6385
10	self-monitoring/	2883
11	exp assistive technology/	9925
12	(assistive technolog* or co care or self care or self help device* or self management* or self monitor* or self track*).ti,ab,id.	24688
13	or/5-12	103132
14	4 and 13	683
15	(co innovat* or patien*t innovat* or patient design*).ti,ab,id.	82
16	14 or 15	760

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4. Cinahl

Interface: Ebsco Date of Search: 15 October 2019 Number of hits: 2,391	Field labels • MH+ = exploded Cinahl Heading • MH = non exploded Cinahl Heading • TI = title • AB = abstract • Nx = within x words, regardless of order • * = truncation of word for alternate endings

#	Searches	Results
S14	S12 OR S13	2,391
S13	TI ("co innovat*" or "patient* innovat*" or "patient design*") OR AB ("co innovat*" or "patient* innovat*" or "patient design*")	144
S12	S4 AND S11	2,255
S11	S5 OR S6 OR S7 OR S8 OR S9 OR S10	184,189
S10	TI ("assistive technolog*" or "co care" or "self care" or "self help device*" or "self management*" or "self monitor*" or "self track*") OR AB ("assistive technolog*" or "co care" or "self care" or "self help device*" or "self management*" or "self monitor*" or "self track*")	29,539
S9	(MH "Assistive Technology Devices+")	31,412
S8	(MH "Self Care+")	44,835
S7	TI (innovat* or invention* or invented) OR AB (innovat* or invention* or invented)	49,209
S6	(MH "Diffusion of Innovation+")	12,735
S5	(MH "Equipment Design+")	43,859
S4	S1 OR S2 OR S3	23,406
S3	(MH "Consumer Participation")	17,926
S2	TI ("co design*" or "co creat*" or "collaborative creation*" or "collaborativ* created" or "do it yourself" or "doing it for themselves" or diy or "e patient*" or "lead patient*" or "participatory design*" or "public driven" or superuser*) OR AB ("co design*" or "co creat*" or "collaborative creation*" or "collaborativ* created" or "do it yourself" or "doing it for themselves" or diy or "e patient*" or "lead patient*" or "participatory design*" or "public driven" or superuser*)	2,321
S1	TI (("adult child*" or patient* or "care giver*" or caregiver* or carer* or family or husband* or "next of kin*" or partner* or spouse* or user or wife or wives) N1	3,379

	(directed or driven or driving or initiated)) OR AB (("adult child*" or patient* or "care giver*" or caregiver* or carer* or family or husband* or "next of kin*" or partner* or spouse* or user or wife or wives) N1 (directed or driven or driving or initiated))	

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Publication	Country*	Publication type	*Publication type categorized*	Study aim	*Study aim categorized*
Ahrens 2016	USA	Special section	*8 Special section dedicated to patients*	N/A	*N/A*
Ardolino 2017	USA	Case report	*1 Original research*	"to report the effect of a home-based dynamic standing program on postural control and gross motor activity in 2 children with trunk hypotonia"	*5 Test effect/impact of innovation*
Barnard 2018	UK	Commentary	*4 Letter to editor/commentary*	"discuss the challenges faced by key stakeholder groups in terms of potential collaboration and open debate of these challenges"	*4 Describe how users perceive the innovations*
Beckman 2016	Norway	Conference abstract	*5 Conference abstracts*	"propose how to extend the Nightscout application with motivational mechanisms and social media functionality for small user groups"	*5 Test effect/impact of innovation*
Ben-Pazi 2018	Israel	Research article	*1 Original research*	To investigate the impact of auditory stimulation on motor function in children with cerebral palsy (CP) and disabling hypertonia.	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Berry 2019	USA	Clinical trial	*1 Original research*	"The purpose of this randomized pilot trial was to compare post-operative pain intensity, over the weeks that participants had surgical drains, between those receiving the Jacki Jacket plus usual care (Jacki + UC) and UC alone. Secondary outcomes included pain interference, functional status, self-administered pain medication, time to opioid cessation, quality of life, and related breast cancer symptoms."	*5 Test effect/impact of innovation*
Braune 2019 DIWHY	Germany	Short paper	*2 Short report*	There remains, however, a lack of research examining outcomes of children and adolescents with DIYAPS in everyday life and their social context. This survey assesses the self-reported clinical outcomes of this specific user group.	*5 Test effect/impact of innovation*
Braune 2019 Real World Use	Germany	Conference abstract	*5 Conference abstract*	This study aims to examine the	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				motivations of Do-it-Yourself Artificial Pancreas System (DIYAPS) users and caregivers to build and maintain these systems.	
Brownstein 2009	USA	Letter to editor	*4 Letter to editor/commentary*	Promoting PLM in OI community; Questions: "1. Can social networking make patients' lives better? 2. Where do we need to go? (i.e., How would a specific bone disorder community work? Is it possible for patients to know how well they are doing in comparison to others like them, and if they are getting the most successful treatment for their disease?)" 3. How do we get there? (What do we need to do?)	*1 Describe the innovation*
Brownstein 2010	USA	Symposium (commentary)	*4 Letter to editor/commentary*	Same as Brownstein 2009	*1 Describe the innovation*
Burnside 2020 Do-it-yourself	New Zealand	Symposium proceedings	*7 Review*	"deliver examples of research in artificial pancreas technology which actively pursues the use of machine learning	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				representative of artificial intelligence (AI) and also explore alternate approaches to AI within the DIY AID example." "examine data sharing for algorithm development and refinement, for sharing of the open-source algorithm codes online, for peer to peer support, and sharing with medical and scientific communities."	
Chiauzzi 2019 Digital Trespass	USA	listed as "Article"	*1 Original research*	"...share four cases involving ethical and terms-of-use violations" [to address the following questions about challenges and ethics violations while using social media and "big data" for research:] "How do these ethical violations occur? How are these violations discovered and remedied by data producers? Most importantly, what corrective actions can and should be taken to prevent violations	*6 Describe/discuss ethical issues*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				that compromise the privacy of social media users?" "goal is to utilize these cases as a springboard to protect patient privacy while finding ways of meeting investigators' legitimate public health research objectives."	
Cleal 2019	Denmark	Conference abstract	*5 Conference abstract*	detailing the lived experiences of people using DIYAPS in an extensive and diverse way.	*4 Describe how users perceive the innovations*
Crabtree 2019 DIY artificial pancreas	UK	Review	*7 Review*	"discuss the principles of DIY APS, the outcomes observed so far and the feedback from users, and debate the ethical issues which arise before looking to the future and newer technologies on the horizon"	*2 Describe development of innovation* *6 Describe/discuss ethical issues*
De Bock 2019	New Zealand	Editorial	*6 Editorial*	"(i) What safety and efficacy data exist? (ii) What legal implications are there when providing care for a patient who uses an unregulated product? and (iii) What is the role of the	*7 Describe/discuss policy change*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				healthcare professional with respect to adjusting/prescribing or education where there is none of the usual training or support infrastructure available? The purpose of this editorial is to update clinicians on these critical aspects. "	
De la Loge 2016	Belgium	Research article	*1 Original research*	"The objective of this retrospective analysis was to characterize the profile of users and their disease and identify factors predictive of poor health-related quality of life (HRQoL), while assessing the platform's potential in providing patient-reported data for research purposes."	*3 Describe users, 5 Test effect/impact of innovation*
De Monestrol 2018	Sweden	Conference abstract	*5 Conference abstract*	As new life-changing, yet expensive, therapies for cystic fibrosis(CF) become available, Sweden and its responsible authorities strive to create a system that enables structured	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				follow-up and evaluation of new treatments for optimal care and best use of resources. In 2016, key CF stakeholders formed the Sweden CF Coalition, a national collaborative learning network that enables persons with CF, families, clinicians, researchers and others to work together toward common goals. The Coalition aims to reduce the burden of illness for patients by radically improving the ability of patients, families and professionals to co-produce improved clinical practice and better care at home.	
Debong 2019	Austria	peer review "EMERGING DIGITAL HEALTH TECHNOLOGIES IN DIABETES"	*1 Original research*	"discuss findings from real world observations of changes in glycemic control and patient satisfaction associated with the use of the mHealth app"	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Dowling 2020 Do-it-yourself closed-loop	UK	Position statement	*4 Letter to editor/commentary*	"This position statement recognizes that the development of diabetes technology is a rapidly changing environment, and guidance around do-it-yourself systems is required from professional and regulatory bodies." ("Diabetes UK's position statements make recommendations that aim to provide guidance for both people with diabetes and healthcare professionals, based on the current professional and legal situation.")	*7 Describe/discuss policy change*
Ellis 2013	Australia	Conference proceedings	*1 Original research*	"...the aim was to primarily focus on how these sites [PatientsLikeMe and HealthShare [http://www.healthshare.com.au/]] described and subsequently supported patient-to-patient interactions to support self-management"	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Farrington 2016	USA	"In focus"	*4 Letter to editor/commentary*	N/A	*N/A*
Fergus 2017	USA	Peer review	*1 Original research*	"to assess the feasibility and describe the gait outcomes associated with the use of the Upsee in conjunction with KT for a young child with extrapyramidal CP"	*1 Describe the innovation*
Frost 2008 How the social	USA	Symposium proceedings	*1 Original research*	"This paper reports on... - how people with ALS, and their physicians, leveraged community, data sharing, and the Internet to accelerate the evaluation of a treatment and conduct a real time open investigation on the effects of Lithium on disease progression."	*1 Describe the innovation*
Frost 2008 Social uses of	USA	Research article	*1 Original research*	"how patients explicitly utilize visual displays of health information to communicate with specific patients about their treatments and disease experience. We also sought to describe the kind of dialogues that emerge	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				when individual health information is made available within a patient community."	
Frost 2009 Patients like me the case	USA	Review Series: Tele-eHealth	*1 Original research*	"The goal of this paper is to present a case exemplar on how amyotrophic lateral sclerosis (ALS) patients are using PatientsLikeMe to inform decisions related to pulmonary health. What happens when the patients go online to share not only their insights and support of one another but also structured health information?"	*5 Test effect/impact of innovation*
Grande 2019 Empowering young people	Sweden	Original paper	*1 Original research*	"to examine how an mHealth patient support system (mPSS) might foster partnership between young people living with JIA, their families, and care teams"	*4 Describe how users perceive the innovations*
Griffiths 2015 The impact of	UK	Research article	*7 Review*	"What is the potential for impact of health-related, lay-controlled networked digital	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				communication on health and health systems?" "In our case studies we consider the balance between these different activities and their impact on health, health care, and health care policy." "For the scoping review, we establish the extent to which the phenomenon of social networks related to health is documented in the publically available literature, and establish evidence of the prevalence of these networks." "In order to select our case studies, we describe the characteristics of documented networks and how they vary. We then select four networks as case studies..."	
Heywood 2014 Straight talk with	USA	Interview with Jamie Heywood, co-founder of PLM	*6 Editorial*	N/A	*N/A*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Hng 2018 Appearence of do-it-yourself	Australia	Peer review	*1 Original research*	"to describe the Australian looping community, specifically to understand who they are, their motivations for the DIY approach and the challenges faced by these individuals and their HCP"	*3 Describe users*
Hussain 2020 Part I	UK	podcast transcript (Editorial)	*6 Editorial*	N/A	*N/A*
Hussain 2020 Part II	UK	podcast transcript (Editorial)	*6 Editorial*	N/A	*N/A*
Janssen 2016 A painted staircase	Netherlands	Letter to the editor	*4 Letter to editor/commentary*	"we regard this case description as a homage to the inventiveness of patients and their caregivers"	*3 Describe users*
Janssen 2016 Response to	Netherlands	Response: Letter to the editor	*4 Letter to editor/commentary*	N/A	*N/A*
Jennings 2020 Do-It-Yourself Artificial Pancreas	UK	Symposium proceedings/Review	*7 Review*	"First, it synthesizes the emerging literature on DIY APS and identifies a range of evidence including research, reviews, commentaries, and opinion pieces written by DIY APS users, healthcare professionals (HCPs),	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				and researchers. It summarizes the emerging clinical evidence for DIY APS and provide insight into how the DIY APS movement began, has been disseminated throughout diabetes online communities, and is reshaping self-management of T1D in real-world settings. Second, the article provides commentaries that explore implications of DIY APS to healthcare practice."	
Kendall 2017 T1resources.uk	UK	Peer-review ("current topics")	*1 Original research*	"to provide a curated library of resources created for and by people with T1DM. The website is co-curated, with equal healthcare professional and peer representation and input. "	*2 Describe development of innovation*
Klee 2018 An intervention by	Switzerland	Original article	*1 Original research*	"to evaluate the impact of a multidisciplinary intervention consisting of using Webdia, a patient-designed mHealth app,	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				combined with an educational intervention by specialized nurses and regular insulin dose adaptation by diabetologists on metabolic control of T1DM, QoL, and frequency of hypoglycemia in children 10–18 years of age, followed at the outpatient clinic of the pediatric diabe- tology unit of the University Hospitals of Geneva, Switzerland"	
Kontovounisios 2018 The Ostom-i alert	UK	Other ("Technical advances")	*1 Original research*	"to assess the efficacy and usability of Ostom-i ™ sensor, clipped to the lower part of a stoma bag to sense when a bag is filling and to relay that data back to the patient in real time via a smartphone application"	*1 Describe the innovation0*
Kublin 2020 The Nightscout system	Poland	Review paper	*7 Review*	"This article describes the Nightscout system – required components, operating costs, and	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				other usage options. It also presents the current evaluation of the Nightscout system in scientific publications."	
Lawlor 2017 Developing integrated care	Ireland	Conference abstract	*5 Conference abstract*	"The shared aim is to develop a clinical network, center of expertise and care pathway for 22q11.2DS informed by carers and service users, building upon existing specialist expertise within the health system. "	*2 Describe development of innovation*
Lebental 2011 Patient perception	USA	Original paper	*1 Original research*	"This study evaluated treatment satisfaction, comfort, and function using the wireless OmniPod Insulin Management System (Insulet Corp., Bedford, MA) compared with conventional (infusion set) insulin pumps in young adults with type 1 diabetes."	*4 Describe how users perceive the innovations*
Lee 2016 A patient-designed	USA	"Viewpoint" Opinion	*4 Letter to editor/commentary*	"This Viewpoint describes the Nightscout Project, including the challenges it poses for the current healthcare	*1 Describe the innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				system, and the opportunities yielded from this new form of health production	
Lee 2017 Real-world use	USA	Original article	*1 Original research*	"to compare demographic/disease characteristics of users versus nonusers of a do-it-yourself (DIY) mobile technology system for diabetes (Nightscout), to describe its uses and personalization, and to evaluate associated changes in health behaviors and outcomes."	*3 Describe users,5 Test effect/impact of innovation*
Lemieux 2020 Do-It-Yourself Artificial Pancreas	Canada	Abstract	*5 Conference abstract*	"Despite considerable effort, few pregnant women with type 1 diabetes achieve the tight glycemic control required in pregnancy. Use of DIY APS is growing, but little is known about their safety and efficacy during pregnancy….We describe a 31-year-old G3P1SA1 with type 1 diabetes of 22 years duration, who used a “loop” system in pregnancy."	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Lewis 2015 How a DIY	USA	Conference abstract	*5 Conference abstract*	N/A	*N/A*
Lewis 2016 Real-world use	USA	Letter to the editor	*4 Letter to editor/commentary*	N/A	*N/A*
Lewis 2017 Automatic estimation	USA	Conference abstract	*5 Conference abstract*	N/A	*N/A*
Lewis 2018 Detecting insulin	USA	Conference abstract	*5 Conference abstract*	Not reported	
Lewis 2018 Improvements in A1C	USA	Conference abstract	*5 Conference abstract*	To compare mean BG, TIR (70-180 mg/dl), and time above and below clinically meaningful thresholds before and after OpenAPS initiation	*5 Test effect/impact of innovation*
Lewis 2018 Setting expectations	USA	Letter to the editor	*4 Letter to editor/commentary*	N/A	*N/A*
Lewis 2019 Characterization of	USA	Conference abstract	*5 Conference abstract*	This is the first longitudinal analysis of biological rhythms in T1D, compared to non-T1D individuals	*5 Test effect/impact of innovation*
Lewis 2019 History and perspective	USA	Commentary	*4 Letter to editor/commentary*	"This commentary will address DIY closed looping: how it was developed and how it works; potential benefits and documented outcomes from and by this self-selected population; potential disadvantages of this approach; and	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				perspective on where DIY is going and how it effects other diabetes technology development."	
Li 2013 Privacy policies for	USA	Perspective	*4 Letter to editor/commentary*	"The aim of this study is to identify and sketch the policy implications of using HSNS and how policy makers and stakeholders should elaborate upon them to protect the privacy of online health data."	*7 Describe/discuss policy change*
Lindblad 2019 Sweden's learning	Sweden	Conference abstract	*5 Conference abstract*	As new life-changing, yet expensive, therapies for cystic fibrosis (CF) become available, Sweden's stakeholders strive to build a system for structured follow-up and evaluation of new treatments for optimal care and best use of resources.	*2 Describe development of innovation*
Litchman 2019 Twitter analysis	USA	Symposium/ Special Issue	*1 Original research*	" to examine Twitter data to understand how patients, caregivers, and care partners perceive OpenAPS, the personal and emotional ramifications of using	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				OpenAPS, and the influence of OpenAPS on daily life"	
Litchman 2020 Patient-Driven Diabetes Technologies	USA	Research article	*1 Original research*	"the purpose of this study was threefold. First, examine the #WeAreNotWaiting and #OpenAPS tweets to understand the sentiment (positive and negative) among different stakeholder groups. Second, to examine highly shared photos to understand visual representations of DIY patient-led innovations. Finally, determine the personas who engage in DIY patient-led diabetes technologies activities and conversations on Twitter. This study will provide insight into diabetes-specific DIY patient-led innovations that may influence or inform patient-led efforts in other disease states."	*3 Describe users*
Longacre 2018 Clinical adoption	Sweden	Original paper	*1 Original research*	"This study explored the development, adoption, and integration of a new,	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				co-produced mHealth platform (Genia) for the management of pediatric CF in Sweden."	
Ma 2015 Mental disorder recovery	USA	Research article	*1 Original research*	"To test whether social behavior and well-being are also associated in online communities [as they are in real-world communities], we studied the correlations between the recovery of patients with mental disorders and their behaviors in online social media."	*5 Test effect/impact of innovation*
Mader 2015 Influence of	Austria	Conference abstract	*5 Conference abstract*	The aim of this retrospective analysis was to investigate whether we can determine characteristics of adherent (=4 BG values/day on an active day) and non-adherent (<4 BG values/day on an active day) mySugr users	*5 Test effect/impact of innovation*
Marshall 2019 Do-it-yourself	UK	Commentary	*4 Letter to editor/commentary*	"we provide the perspectives of two adults with T1D, the parent of a child with	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				T1D and three physicians who detail their experience with these systems. These personal and clinical perspectives highlight very clear metabolic and psychological benefits of these systems in real-world settings."	
Melmer 2019 Glycaemic control	Switzerland	Brief report	*2 Short report*	"In the present study, we describe glycaemic control in individuals with type 1 diabetes using OpenAPS. In a subcohort, we analyzed differences in glycaemic control after switching from standard sensor-augmented pump therapy (SAP) to OpenAPS."	*5 Test effect/impact of innovation*
Melmer 2019 In-depth review	Switzerland	Conference abstract	*5 Conference abstract*	The present study evaluated glycemic control and glycemic variability of CGM readings of 80 DIY closed loop users	*5 Test effect/impact of innovation*
Murray 2020 Health Care Provider	USA	Research article	*1 Original research*	"The purpose of this study was threefold: (a) to assess the perceived need among health care providers (HCPs) for a	*7 Describe/discuss policy change*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				comparison fact sheet of FDA-approved and DIY AID technology; (b) to develop an updated and relevant fact sheet of most commonly used FDA-approved and DIY AID technology; and (c) to assess the relevance of content and usefulness of fact sheet to HCPs. This study has the potential to reduce barriers to AID technology uptake by increasing HCP's awareness and understanding of AID options."	
Ng 2020 Evolution of Do-It-Yourself	USA	Research article	*1 Original research*	"the objectives of this study were to identify and describe the different types of patient-designed DIY innovations in the T1D community focused on Nightscout, and to describe the timeline of innovations in comparison with similar features available in commercial products. In addition, we evaluated metrics	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				related to code use and contributions to open-source code repositories for Nightscout."	
O'Brien 2019 Patient perspectives on	USA	Research article	*1 Original research*	"To examine the patient perspective on the risks and benefits of linking existing data sources for research."	*4 Describe how users perceive the innovations*
O'Connor 2017 The MediStori	Ireland	Conference abstract	*5 Conference abstract*	" The aim for this research project was to gain valuable insights and domain knowledge on how best the toolkit, MediStori, could be utilised to improve integrated care processes and person centred models of care"	*1 Describe the innovation*
O'Donnell 2019 Evidence on	Ireland	Protocol	*3 Protocol*	The overall aim of this study is to establish the empirical evidence base for the clinical effectiveness and quality-of-life benefits of DIYAPS and identify the challenges and possible solutions to enable their wider diffusion.	*5 Test effect/impact of innovation*
Okun 2017 Building a learning	USA	Experience report	*4 Letter to editor/commentary*	"describes the development of the Patient and Caregiver	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				Journey Framework and related patient-informed principles for design and measurement created by PatientsLikeMe in partnership with patients and caregivers"	
Okun 2018 DigitalMe: A journey	USA	Commentary	*4 Letter to editor/commentary*	Reports on a partnership with iCarbonX and Digital Life Alliance. "DigitalMe Ignite, a PLM pilot study launched in June 2017, will integrate methods to measure how well an individual's body and mind are doing (health) and how well an individual is living the life she wants (thrive)."	*1 Describe the innovation*
Oliver 2019 Open source automated	UK	Perspective	*4 Letter to editor/commentary*	"we explore some of the ways that a multidisciplinary approach may unlock the potential for open source solutions to be implemented more widely for people with T1DM in a way that is acceptable to all stakeholders, while ensuring sensitivity to	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				the priorities of existing users"	
Omer 2016 Empowered citizen	UK	Commentary	*4 Letter to editor/commentary*	N/A	*N/A*
Pearson 2011 Potential for electronic	USA	Review	*7 Review*	"This review addresses the use of EHRs in research, the potential of PHRs and online social networking to improve health, and what this means for the future of health outcomes and diabetes research."	*5 Test effect/impact of innovation*
Riggare 2015 Patients organize	Sweden	Personal view	*4 Letter to editor/commentary*	We both have Parkinson's disease and experience a complex array of motor and non-motor symptoms. Here is a glimpse at the invisible work that, in our experience, leads to better care.	*N/A*
Rivard 2020 It's not just	Canada	Original research	*1 Original research*	"we gathered the views of experts in related fields with a focus on how two innovations—Nightscout Project6 25–30 33 and e-NABLE10 13 14 34—impact quality and safety concerns"	*7 Describe/discuss policy change*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Rouholiman 2018 Improving health-related	USA	Protocol	*3 Protocol*	"In the present study, we plan to assess the quality of life of ostomy patients using the Ostom-i alert sensor, a portable, wearable, Bluetooth-linked biosensor that facilitates easier ostomy bag output measurements. We hypothesize that using the Ostom-i alert sensor will result in an improved, ostomy-specific, health-related quality of life as compared to baseline measurement before the use of the sensor."	*5 Test effect/impact of innovation*
Rundle 2018 PatientsLikeMe and atopic	USA	Commentary	*4 Letter to editor/commentary*	"This retrospective analysis looks to characterize the AD patient profile to better assess features of the AD community and appraise PatientsLikeMe data with current AD literature."	*3 Describe users*
Sahama 2012 Impact of the	Australia	Original article	*1 Original research*	"In this paper we propose a framework for multiple profile management of online social networks and showcase a	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				demonstrator utilising an open source platform."	
Schroeder 2015 An Innovative Approach	USA	Research article	*1 Original research*	"(1) to identify issues in diabetes management that PatientsLikeMe patient stakeholders find difficult or important in the following domains: accessing diabetes care, communication with providers, medication management, lifestyle behaviors, and personal relationships; (2) to gather an array of patient perspectives that would inform, amplify, and supplement the findings from the in-person stakeholder meeting; and (3) to assess the pragmatic usefulness of online surveys for conducting diabetes research among an SNS population."	*4 Describe how users perceive the innovations, 7 Describe/discuss ethical issues*
Seres 2017 From patient to	USA	Special section "in my own voice"	*8 Special section dedicated to patients*	N/A	*N/A*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Shaw 2020 The DIY artificial	Switzerland	Commentary	*4 Letter to editor/commentary*	"The question of how doctors should navigate these ethical issues when discussing care with patients needs to be addressed."	*7 Describe/discuss policy change*
Shepard 2020 User and healthcare	USA	Commentary	*4 Letter to editor/commentary*	"to obtain stakeholder perspectives on DIY APS in order to inform the development of guidelines for clinical practice."	*4 Describe how users perceive the innovations*
Smith 2008 PatientsLikeMe: Consumer health	USA	Symposium proceedings	*1 Original research*	"An old research question with new implications for Web developers is this: What language do patients use to describe their conditions? And what are the implications of patient- and consumer-contributed terms for patient- and consumer-oriented information systems?"	*4 Describe how users perceive the innovations*
Torous 2017 Patient-driven innovation	USA	Editorial / Patient Perspective	*6 Editorial*	"in order to educate and inspire others."	*2 Describe development of innovation*
Trevena 2011 PatientsLikeMe and the	Australia	“Perspectives”	*4 Letter to editor/commentary*	N/A	*N/A*
Vaidyam 2020 Patient innovation	USA	Personal perspective	*8 Special section dedicated to patients*	"Highlighting the potential of health software beyond	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				smartphones (apps), this case report demonstrates the potential for such software to transition between different devices and hardware toward better serving people. Building off a prior case report where an individual started with an app to track symptoms but found a tally counter more useful [2],here we discuss a case where an app was used at first, followed by a transition to a novel device that proved to be a more comprehensive solution."	
White 2018 Motivations for participation	USA	Original article	*1 Original research*	"to describe individuals' motivations for participation in an online social media community and to assess their level of trust in medical information provided by medical professionals and community members"	*4 Describe how users perceive the innovations*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

Wicks 2010 Sharing health-data	USA	Original paper	*1 Original research*	"to describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes"	*1 Describe the innovation*
Wicks 2012 Perceived benefits	USA	Original paper	*1 Original research*	"to gather feedback on perceived benefits from use of our online service by people with epilepsy"	*4 Describe how users perceive the innovations*
Wicks 2014 Could digital patient	USA	Commentary	*4 Letter to editor/commentary*	N/A	*N/A*
Wicks 2014 Data donation could	USA	Commentary	*4 Letter to editor/commentary*	N/A	*N/A*
Wicks 2014 Quality of life	USA	Original research article	*1 Original research*	"to describe and contrast data collected through an online community with the broader organ transplant population"	*3 Describe users*
Wicks 2014 Subjects no more	USA	Observations	*1 Original research*	N/A	*N/A*
Wicks 2018 Patient study thyself	USA	Editorial	*6 Editorial*	N/A	*N/A*
Williams III 2019 The PatientsLikeMe Multiple	USA	Original article	*1 Original research*	"This paper examines how the company successfully expanded its platform beyond its flagship ALS community to other	*2 Describe development of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				communities, specifically one for patients with multiples clerosis (MS). It discusses how PatientsLikeMe®used a strategic market segmentation plan inspired by a motivational theory to attract and engage members, while helping change the paradigm of health data privacy in the USA by endorsing a policy of openness."	
Zabinsky 2020 Do-it-yourself	USA	Conference abstract	*5 Conference abstract*	"There have been few studies comparing glycemic outcomes for DIYAPS compared to conventional sensor-augmented pump (SAP) therapy."	*5 Test effect/impact of innovation*
Zisser 2011 Novel methodology	USA	Original article	*1 Original research*	"The FDA believed there was a need for additional bench test data to support the accuracy of the OmniPod at the smallest delivery volume. To address this concern, we implemented method 1 (discussed later), to measure the accuracy	*5 Test effect/impact of innovation*

Appendix 3.1. Extracted data by article with categorizations for Publication type and Study aim

				of the OmniPod using a standard graduated pipette. "	
Årsand 2016 Warning: the do-it-yourself	Norway	Conference abstract	*5 Conference abstract*	"urge the research society, as well as personnel and decision makers in health care, to be more aware of and open toward the opportunities this new situation brings."	*7 Describe/discuss policy change*

*First author affiliation

Appendix 3.2. Extracted data by article

Publication	Study design	*Study design categorized*	Data	Sample size
Ahrens 2016	patient-driven n-of-1 study	*3 Experimental*	self-tracking symptoms: gut pain, bowel movements, and blood in my stool	1
Ardolino 2017	Case series	*1 Descriptive*	points on (1) the Segmental Assessment of Trunk Control (SATCo)16 and (2) the Gross Motor Function Measure (GMFM-66). And parents reports of changes in childrens behavior	2
Årsand 2016 Warning: the do-it-yourself	"summary is based on the authors' active participation in relevant social media and long research experience within the chosen disease case. We also searched for information on PubMed.gov and Google.com, using keywords "do it yourself" and "diabetes"."	*1 Descriptive*	"information on PubMed.gov and Google.com, using keywords "do it yourself" and "diabetes""	N/A
Barnard 2018	Not specified	*4 No design*	No data	N/A
Beckman 2016	Not specified	*4 No design*	No data	N/A
Bedlack 2019	"12-month open-label clinical trial designed to be semi-virtual"	*3 Experimental*	Enrollment and retention rates; ALSFRS-R, ALS	Participants = 50; "Playing

Appendix 3.2. Extracted data by article

			reversals, perceived efficacy; weight, adverse events, side effects; hystone acetylation; accuracy, adherence, compliance; "Playing along at Home " cohort's demographcis, effectiveness, side effects, adherence.	along at home" = 54
Ben-Pazi 2018	A matched pair double blind randomized control study	*3 Experimental*	Outcome measures: Care and Comfort Hypertonicity Questionnaire (CCHQ), Goal attainment scale (GAS), Gross motor function measure (GMFM-88), Quality of upper extremity skills test (QUEST)	n=22 (11 pairs of children)
Berry 2019	RCT	*3 Experimental*	SDS pain items, Frequenc y Intensity QLQ-C30 Global QOL Physical function Role	139 (84%) were enrolled and randomized (67 UC and 72 Jacki + UC)

Appendix 3.2. Extracted data by article

			function Emotional function Cognitive function Social function Symptom pain QLQ-BR32 Body image Sexual functioning Sexual enjoyment Future perspective Side effects Breast symptoms) Arm symptoms Upset by hair loss	
Bove 2013	"I) compared the demographic characteristics of subjects from PLM [Patients Like Me] and from a regional MS center. II) validated PLM's patient-reported outcome measure (MS Rating Scale, MSRS) against standard physician-rated tools.	*2 Observational*	Demographics; disease (MS) characteristics; patient-reported MS Rating Scale (MSRS); physician-rated tools;	I. PLM MS Center Comparison: Patients Like Me (PLM) - N=10255; Partners MS Center - N=4039 II. Validation of Patient Reported MSRS: N=121 III. BMI and Disease Course: N=10433

Appendix 3.2. Extracted data by article

Braune 2019 DIWHY	Online Survey (Descriptive/Observational)	*1 Descriptive*	Survey data	209
Braune 2019 Real World Use	Online survey	*1 Descriptive*	Survey data	1058
Brownstein 2009	N/A	*N/A*	N/A	N/A
Brownstein 2010	N/A	*N/A*	N/A	N/A
Burnside 2020 Do-it-yourself	N/A	*N/A*	N/A	N/A
Chiauzzi 2019 Digital Trespass	Case studies: "These violations involved the use, interpretation/misinterpretation, and dissemination of patient self-reported data and forum posts available at PatientsLikeMe [40]."	*1 Descriptive*	"...four cases provide examples of ethical and methodological issues that arise when researchers gather social media data without observing the website's terms of use."	4
Cleal 2019	Online survey	*1 Descriptive*	responses to open-ended questions	656
Crabtree 2019 DIY artificial pancreas	N/A	*N/A*	N/A	N/A
De Bock 2019	N/A	*4 No design*	estimated seven million hours of realworld experience with this technology,2 demonstrated remarkable	"Real-world data from an estimated global population of more than 1000 DIY users, and an

Appendix 3.2. Extracted data by article

			glycaemic outcomes.3–6 The limitation to these data is that these individuals are highly motivated and are likely to do well; nevertheless, when compared with their own glycaemic data prior to using the DIY system, time in normal glycaemic range (4–10 mmol/L) improved by 16.4%.5	estimated seven million hours of realworld experience with this technology,2 demonstrated remarkable glycaemic outcomes"
De la Loge 2016	Retrospective analysis	*2 Observational*	Sociodemographics; symptom checklist; treatment history; "validated, standardized patient-reported outcome (PRO) instruments, namely, the Quality of Life in Epilepsy Inventory (QOLIE-31/P) [14], the Hospital Anxiety	7

Appendix 3.2. Extracted data by article

			and Depression Scale (HADS) [15], and the EuroQoL 5-Dimensions Scale, 3 Levels (EQ-5D-3L) [16]."	
De Monestrol 2018	presentation of a CF coalition	*4 No design*	N/A	N/A
Debong 2019	"observations of changes in glycemic control and patient satisfaction associated with the use of the mySugr mHealth app"	*3 Experimental*	"changes in mean blood glucose, SD, CV, eA1c, number of blood glucose tests in range, and frequency of blood glucose testing"	N/A
Dowling 2020 Do-it-yourself closed-loop	N/A	*N/A*	N/A	N/A
Ellis 2013	Simple content analysis	*1 Descriptive*	Content analysis: "examined each site's stated purpose, ownership, design and the information provided on how any data collected is used."	2 social websites (Web 2.0)
Farrington 2016	N/A	*N/A*	N/A	N/A

Appendix 3.2. Extracted data by article

Fergus 2017	Case study (experimental)	*3 Experimental*	User experience, Gait, mPMAL and GMFM	1
Frost 2008 How the social	"mixed methods qualitative and quantitative study of forum posts and treatments adopted by the ALS community after the first report of the Lithium trial in November 2007."	*1 Descriptive*	"All Forum posts including the word “Lithium” were pulled from the site database. We plotted a frequency distribution of Lithium posts. We overlaid that plot with known significant events. We also observed changes in that frequency and used those observations to identify forum posts that appeared to spark those changes."	N=687 posts including word "lithium"
Frost 2008 Social uses of	"design-based qualitative research study" "Using a grounded theory approach [25], a set of codes was developed."	*1 Descriptive*	"user remarks that refer to another’s individual-level personal health data." "comments left on personal profiles." "focus	N=123 comments (derived from 7852 comments)

Appendix 3.2. Extracted data by article

			on how users employ elements of another user's personal health profile in a discussion with that user." "compiling and analyzing the kinds of questions, comments, and discussions that relate directly to shared, personal medical information"	
Frost 2009 Patients like me the case	Case study – qualitative analysis	*1 Descriptive*	"forum content containing preset terms"	Term "bipap" N=1516; Term "trach" N = 1690
Grande 2019 Empowering young people	Semistructured interviews analysed with conventional content analysis	*1 Descriptive*	Interview transcripts from interviews	15 young people, their parents, and 4 care team members
Griffiths 2015 The impact of	Scoping review and case studies.	*1 Descriptive*	Scoping Review: "Characteristics of Social Networking Health Information Sites" [Characteristics of social	23 articles from which 4 social network case studies were selected:

Appendix 3.2. Extracted data by article

			networks found through scoping review.] Case Studies: "describe each case study in terms of its structure, function, participants and impact, how it came into being, how it is sustained, and what has changed as it matured." [PLM is one of the 4 case studies]	
Heywood 2014 Straight talk with	N/A	*N/A*	N/A	N/A
Hng 2018 Appearence of do-it-yourself	Survey	*1 Descriptive*	Experience and other characteristics	19 complete "loopers" (68 answers)
Hussain 2020 Part I	N/A	*N/A*	N/A	N/A
Hussain 2020 Part II	N/A	*N/A*	N/A	N/A
Janssen 2016 A painted staircase	Video-supported case study	*1 Descriptive*	Video	1
Janssen 2016 Response to	N/A	*N/A*	N/A	N/A
Jennings 2020 Do-It-Yourself Artificial Pancreas	Literature search; "experiential learning from our evolving clinical practice"	*1 Descriptive*	various publications; unpublished	24 publications

Appendix 3.2. Extracted data by article

			research; policy statements	
Kendall 2017 T1resources.uk	Article describes how the authors " create a library of useful quality-assured self-care resources"	*4 No design*	"The editorial team identified over 100 online resources which ranged from peer YouTube video clips to personal blogs about eating disorders and NHS created sick-day rules. We began to catalogue them in a shared database, agreeing on a taxonomy with which to categorise the diverse content".	In the first week 1,000 people visited the site, and this continued to grow with 6,500 users in the first six months. Users viewed over 38,000 pages, averaging 3.3 pages per visit and spending 2.50 minute
Klee 2018 An intervention by	"A Randomized Double-Crossover Study"	*3 Experimental*	HbA1C, QoL, hypoglycemic events, satisfaction, usage data, baseline demographics	"Of the 55 included patients, 33 completed the study"
Kontovounisios 2018 The ostom-i- alert	Not described		length of stay, usability, acceptability, QoL	"nine patients [six males, three females,

Appendix 3.2. Extracted data by article

				mean age 52 years (range 26–76 years)]"
Kublin 2020 The Nightscout system	N/A	*N/A*	Review of research articles	N/A
Lawlor 2017 Developing integrated care	"a clinical care coordinator, a lead paediatrician and a family support coordinator will work with service users, families and clinicians to develop and co-ordinate the care pathway in a multidisciplinary network of expertise"	*2 Observational*	N/A (proposal)	N/A
Lebental 2011 Patient perception	"randomized, two-arm open crossover study"	*3 Experimental*	"treatment satisfaction (Diabetes Treatment Satisfaction Questionnaire), user evaluation (OmniPod System User Evaluation Questionnaire), and HbA1c levels"	29
Lee 2016 A patient-designed	N/A	*N/A*	N/A	N/A
Lee 2017 Real-world use	Survey (observational)	*2 Observational*	Demographics, information about use of Nightscout	Members of CGM in the Cloud (n=1268)
Lemieux 2020 Do-It-Yourself	Case study (experimental)	*3 Experimental*	"Case presentation;	1 case

Appendix 3.2. Extracted data by article

Artificial Pancreas			Glycemic control reflected by % time spent in pregnancy target range (TIR) between 3.5-7.8 mmol/L was assessed by continuous glucose monitoring (CGM)."	
Lewis 2015 How a DIY	N/A (descriptive - case report?)	*1 Descriptive*	A1C improved from 7.2 to 6.3 and time in range increased from 51% to 80%	1
Lewis 2016 Real-world use	Survey (descriptive)	*1 Descriptive*	"quantitative and qualitative measures of their experience using their self-built artificial pancreas systems (APSs)"	18
Lewis 2017 Automatic estimation	Survey (descriptive)	*1 Descriptive*	16 users reported feedback about how well this tool ("autotune") works.	16
Lewis 2018 Detecting insulin	Autosens was run retrospectively to obtain an hourly SR value (first calculated SR every hour) for	*2 Observational*	Autosens calculates the deviation for the	12

Appendix 3.2. Extracted data by article

	(N=1)*16 individuals using OpenAPS; with M=5393 data points, and range=922 to 20,473. A SR of >1.0 indicates resistance; <1.0 indicates sensitivity. Histograms were created to visualize SR for each participant. Mean SR ± SD was calculated and those falling beyond ± 10% of 1.0 were classified as being resistant and sensitive respectively		median of the last 8 and 24 hours of CGM data points and determines the sensitivity ratio (SR) required to neutralize the median deviation.	
Lewis 2018 Improvements in A1C	retrospective cross-over analysis of continuous BG readings	*2 Observational*	continuous BG readings recorded during 2-week segments 4-6 weeks before and after initiation of OpenAPS	20
Lewis 2018 Setting expectations	N/A	*N/A*	N/A	N/A
Lewis 2019 Characterization of	Frequency decomposition using the continuous morlet wavelet transformation were created to assess change in rhythmic composition of normalized blood glucose data	*2 Observational*	blood glucose data from 5 non-T1D individuals, and anonymized, retrospective CGM data from 19 T1D individuals using a DIY closed loop APS in the OpenAPS Data Commons	5 non-T1D individuals, 19 T1D individuals

Appendix 3.2. Extracted data by article

Lewis 2019 History and perspective	Survey (descriptive)	*1 Descriptive*	self-reported survey outcomes (sleep, quality of life)	Not reported
Li 2013 Privacy policies for	Paper on policy implications.	*4 No design*	N/A	N/A
Lindblad 2019 Sweden's learning	N/A	*N/A*	N/A	N/A
Litchman 2019 Twitter analysis	Twitter analysis	*1 Descriptive*	Tweets	"3347 tweets generated by 328 patients, caregivers, and care partners"
Litchman 2020 Patient-Driven Diabetes Technologies	"A multiple method qualitative approach"	*1 Descriptive*	"Sentiment analysis"; "Visual document analysis"; "Persona development" using "discourse analysis" (Symplur Signals platform)	N=7886 participants; 46 578 Tweets
Longacre 2018 Clinical adoption	Case study	*1 Descriptive*	"Data sources included interviews, presentations, meeting notes, and other archival documents"	Not reported

Appendix 3.2. Extracted data by article

Ma 2015 Mental disorder recovery	Social network analysis	*2 Observational*	"Recovery outcomes" through social network analysis. [Change over study period in mood, stress, etc.; change in 'life essentials'; Change in symptoms]; "Correlation coefficient matrix between six node properties and five recovery outcomes." "Correlation coefficients between online social activities and recovery outcomes."	200
Mader 2015 Influence of	compare characteristics of adherent (=4 BG values/day on an active day) and non-adherent (<4 BG values/day on an active day) mySugr users	*2 Observational*	Age, Pen use, Blood glucose	728 adherent users on 31,985 days and 475 non-adherent users on 5,132 days were included
Marshall 2019 Do-it-yourself	N/A	*N/A*	N/A	6

Appendix 3.2. Extracted data by article

Melmer 2019 Glycaemic control	"descriptive study of user-donated CGM records obtained before and during use of an open source AP system"	*1 Descriptive*	continuous glucose monitoring (CGM) records	80
Melmer 2019 In-depth review	descriptive analysis of open source APS data	*1 Descriptive*	CGM readings	19251 days (53 years) of CGM readings with a mean duration of 134 days per patient
Murray 2020 Health Care Provider	"two-phase cross-sectional observational study"	*2 Observational*	Paper survey; online survey	Phase I N=43 local HCPs; Phase II N=137 national HCPs
Ng 2020 Evolution of Do-It-Yourself	Thematic analysis of social media posts	*1 Descriptive*	"posts and comments in the “CGM in the Cloud” private Facebook group as well as data from Twitter, GitHub, and the Nightscout website" "list of identified innovations, the need or purpose, and a description of the features/improvements"	Unclear
Nyman 2020 Characteristics and Symptom	Retrospective Observational Study	*2 Observational*	Summary statistics on self-reported patient data "from PLM	21101

Appendix 3.2. Extracted data by article

			members with SLE to characterize demographics, clinical characteristics, symptom severity, primary lupus manifestations, comorbidities, and treatment."	
O'Brien 2019 Patient perspectives on	Questionnaire study - sent to all PLM members active within previous 90 days.	*1 Descriptive*	Demographics; primary medical condition; "respondents' overall comfort levels with sharing health data for research."; "“How much would the removal of the following [various identifying information] increase your comfort level with confidentially sharing your health data?”; "Potential strategies that may improve	3516

Appendix 3.2. Extracted data by article

			levels of comfort with data sharing for research."	
O'Connor 2017 The medistori	presentation of a toolkit	*1 Descriptive*	N/A	N/A
O'Donnell 2019 Evidence on	"Quantitative and qualitative methodologies will be used to examine clinical and self-reported outcome measures of DIYAPS users."	*2 Observational (protocol)*	N/A	N/A
Okun 2017 Building a learning	"qualitative research methods, immersive observation and directed one-on-one conversations." Interviews with patients and caregivers: "The team developed an interview guide heavily influenced by techniques used in ethnographic interviewing, a qualitative research method that combines immersive observation and directed one-on one conversations."	*1 Descriptive*	[Arrived at 6 common questions based on thematic categories. Developed a group of 'personas' based on their thematic qualitative interview data.] "The personas created for PatientsLikeMe were synthesized from the team's research and ethnographic interviews to represent the diversity of behaviors, preferences, and	29

Appendix 3.2. Extracted data by article

			characteristics of patients and caregivers."	
Okun 2018 DigitalMe: A journey	Unclear	*N/A*	No data are presented but describes data collection for "a new patient-reported measure ['Thrive']that could be used across conditions for all members of PLM." "(1) health and symptoms, (2) how well you can do what matters (functioning), and (3) how you're feeling about it (thriving)." Also describes a pilot study in which "The participant experience includes blood specimen collection at the time of enrollment and every 4 months thereafter to	N/A

Appendix 3.2. Extracted data by article

			interrogate the biological state with deep molecular profiling."	
Oliver 2019 Open source automated	N/A	*N/A*	N/A	N/A
Omer 2016 Empowered citizen	N/A	*N/A*	N/A	N/A
Pearson 2011 Potential for electronic	Review	*1 Descriptive*	N/A	N/A
Riggare 2015 Patients organize	N/A	*N/A*	N/A	N/A
Rivard 2020 It's not just	Qualitative interviews with "inductive exploratory thematic analysis approach"	*1 Descriptive*	Information about participants, citations from interviews	"in French (n=14) or in English (n=17)"
Rouholiman 2018 Improving health-related	"prospective, observational, cross-over pilot study"	*2 Observational*	survey data "ostomy-specific, health-related quality of life at baseline (prior to Ostom-i alert sensor use) to ostomy-specific, health-related quality of life after 2 and 4 weeks of Ostom-i use by utilizing the City of Hope	20

Appendix 3.2. Extracted data by article

			Quality of Life Questionnaire for Patients with an Ostomy"	
Rundle 2018 PatientsLikeMe and atopic	Retrospective analysis	*1 Descriptive*	[Self-reported demographics, symptoms, disease history from PLM.]	410
Sahama 2012 Impact of the	[Proposal for internet protocol.]	*N/A*	[Hypothetical scenarios]	N/A
Schroeder 2015 An Innovative Approach	[Web-based survey including quantitative and qualitative.] "The objective of our study was to inform a research priority-setting agenda by using a Web-based survey to gather perceptions of important and difficult aspects of diabetes care from patient members of a social networking site-based community."	*1 Descriptive*	Demographics; Descriptive or summary statistics - disease progression, treatment, complications, other health variables; "patient experience" scales; thematic content analysis.	320
Seres 2017 From patient to	N/A	*N/A*	The authors own story and reflections	N/A
Shaw 2020 The DIY artificial	N/A	*N/A*		
Shepard 2020 User and healthcare	"To explore these complex and controversial issues, we held a workshop at the annual Advanced Technologies and Treatments in Diabetes conference in February 2020."	*1 Descriptive*	"We report a summary of these perspectives" " User Perspectives"	"Approximately 60 stakeholders"

Appendix 3.2. Extracted data by article

			"HCP's Perspectives"	
Smith 2008 PatientsLikeMe: Consumer health	"As of September 2007, 376 symptom terms had been contributed by PatientsLikeMe community members. Two coders working independently analyzed these raw, un-normalized terms for consonance with the Unified Medical Language System (2007 AC) in December, 2007"	*1 Descriptive*	"PatientsLikeMe symptom terms (3 communities): Agreement with the UMLS Metathesaurus"	
Torous 2017 Patient-driven innovation	"The case is cowritten with an individual with schizophrenia, who openly shares his name and personal experience with mental health technology"	*1 Descriptive*	"patient perspective" (case study)	1
Trevena 2011 PatientsLikeMe and the	N/A	*N/A*	N/A	N/A
Vaidyam 2020 Patient innovation	Case report	*1 Descriptive*	air quality and patient's self-tracking of audio hallucinations	1
White 2018 Motivations for participation	Online survey	*1 Descriptive*	Survey data	" to describe individuals' motivations for participation in an online social media community and to assess their level of trust in medical information provided by

Appendix 3.2. Extracted data by article

				medical professionals and community members"
Wicks 2009 Measuring function in	Item development based on survey	*1 Descriptive*	Data on psychometrics of new items. "Baseline item variation and overall scale reliability" "Factor analysis: internal structure of the ALSFRS-R and new items" "Re-test reliability" "Discriminant validity"	Baseline respondents: 326; Re-test respondents: 169; 3-month follow-up respondents: 218
Wicks 2010 Sharing health-data	Online survey	*1 Descriptive*	Survey data	"Complete responses were received from 1323 participants"
Wicks 2011 Accelerated clinical discovery	Observational analysis	*2 Observational*	[ALSFRS-R12 scores in PLM members using lithium and "matched controls".] "ALS disease progression is evaluated using the Revised ALS Functional	"149 patients ... in an 'intent to treat' group (that is, they took lithium but may have discontinued within 12 months) and 78 patients in a... 'full course'

Appendix 3.2. Extracted data by article

			Rating Scale (ALSFRS-R12, henceforth referred to as FRS), which measures patient-reported functional impairment in domains such as speech, swallowing, walking, arm function and respiratory function." "developed an algorithm, the PatientsLikeMe matching algorithm, to match lithium-treated and control patients based on their entire disease progression, as measured by the FRS, before treatment was initiated"	group (that is, a subset of the intent-to-treat group who continued to take lithium for the entire 12 months)."
Wicks 2011 Use of an	Online survey	*1 Descriptive*	Survey data: Demographics; logistic regression on factors affecting adherence;	431

Appendix 3.2. Extracted data by article

			descriptives on adherence; descriptives on "Psychometric performance of Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ) subscale characteristics"; "missed dose ratio (MDR) ... the number of doses missed divided by the number of prescribed doses over a 28-day period" by treatment.	
Wicks 2012 Perceived benefits	Online survey via PLM	*1 Descriptive*	Survey data: "Benefit score"; [various parametric and non-parametric statistical tests]	221
Wicks 2012 The multiple sclerosis	Cognitive interviewing and survey piloting of a MS scale	*1 Descriptive*	Psychometrics; factor analysis; internal consistency; Test-retest.	816

Appendix 3.2. Extracted data by article

Wicks 2014 Could digital patient	N/A	*N/A*	N/A	N/A
Wicks 2014 Data donation could	N/A	*N/A*	N/A	N/A
Wicks 2014 Quality of life	Descriptive study tracking patient outcomes using PLM data from organ transplant recipients.	*1 Descriptive*	Demographics; "transplant history information"; Lab values; Symptoms; Treatments; Quality of life per the PLMQOL; qualitative analysis of forum posts	1924
Wicks 2014 Subjects no more	N/A	*N/A*	N/A	N/A
Wicks 2018 Patient study thyself	N/A	*N/A*	N/A	N/A
Williams III 2019 The PatientsLikeMe Multiple	"The analysis discussed in this paper was conducted by reviewing documents created during the company's expansion period for the platform from one community, amyotrophic lateral sclerosis (ALS), to multiple sclerosis (MS)."	*1 Descriptive*	N/A	N/A
Zabinsky 2020 Do-it-yourself	"A retrospective double cohort study was performed"	*2 Observational*	"The DIY group consisted of people with T1D using DIYAPS (OpenAPS, Loop,	DIY group=74, Control group=98

Appendix 3.2. Extracted data by article

			and AndroidAPS) who contributed data to the OpenAPS Data Commons. The SAP group included age-matched SAP users whose sensor data was obtained through the Tidepool Big Data Donation Project."	
Zisser 2011 Novel methodology	"bench testing" "We implemented two new approaches for assessing pump accuracy. A total of seven OmniPod insulin pumps were tested at bolus doses of 0.05, 0.1, 0.2, 1, and 6 U. Additional materials included a digital microscope (DinoLight, running software DinoXcope v1.1) and a standard 100 µl pipette (equivalent to a 10 U volume of insulin). "	*1 Descriptive*	measures of the size of bolus given by the pumps	2 OmniPods tested

Appendix 3.3. Extracted data by article

Publication	Innovation	Description of Innovation	Innovators names	Medical condition	Unmet needs
Ahrens 2016	Helminth therapy	the author ingested pig worms in two week intervals during 32 weeks	Sean Ahrens	Chron's disease	Symptom management
Ardolino 2017	Upsee	"a harness that a parent can wear on the legs. A child can stand supported in the harness. The harness have joint sandals for both parent and child so they can walk together"	Debby Elnatan (not from article, through google and youtube)	Trunk hypotonia	"the Upsee would be an easy addition to a home program designed to increase standing and weight shifting in children"."Paleg et al 3 suggested pairing upright posture with others with activities that foster communication and participation."
Barnard 2018	DIYAPS	"In the recent years there has emerged a growing movement of PWD innovators rallying behind the mantra #WeAreNotWaiting, developing "do-it-yourself artificial pancreas systems (DIY APS)," which connect existing insulin pumps and CGM sensor systems and close the loop between these devices through automated insulin dosing controlled by a "homemade" algorithm"	N/A	Diabetes T1	"Artificial pancreas" (also known as "closed-loop" and "automated insulin delivery") systems present a promising therapeutic option for people with diabetes (PWD)—simultaneously improving glycemic outcomes, reducing the burden of self-management, and improving health-related quality of life. ".
Beck 2017	Patients Like Me				
Beckman 2016	Nightscout	"The Nightscout project (represented under the name "CGM in the Cloud" at Facebook and other sources) [1] is an open source, DIY (Do It Yourself) initiative that permits real time access to CGM (Continuous Glucose Monitor) data through personal website and smartwatch and smartphones apps. The goal	N/A	Diabetes T1	"multi-user functionality to share blood glucose (BG) data and work together to achieve healthy glucose control. The typical user interfaces present the current BG value and the historical development of the user's BG values for one single user only".

Appendix 3.3. Extracted data by article

		of the Nightscout project is to allow flexible, remote monitoring of a person with type 1 Diabetes' glucose level using existing monitoring devices. Few solutions offer multi-user functionality to share blood glucose (BG) data and work together to achieve healthy glucose control. The typical user interfaces present the current BG value and the historical development of the user's BG values for one single user only".			
Bedlack 2010	Patients Like Me				
Bedlack 2019	Patients Like Me	"wider inclusion criteria, minimal travel burdens by making most of the visits virtual (via the PatientsLikeMe platform), historical controls(rather than placebo), and results made available in real time." "published our protocol on a website (12) so that PALS all over the world with plans to self-experiment (13) could be empowered to try a new treatment with a sound rationale at reasonable dose and to record their own outcome measures online, albeit outside a traditional trial infrastructure."	N/A	ALS	[Difficulty in accessing and frustration with clinical trials due to restrictive inclusion criteria, incovenience, use of placebo, wait times, and thereby difficulty in accessing new or experimental treatments and low enrollment by PALS in trials. Allows patient to collect own data and share it virtually, reduces aforementioned burdens.] "The results of this study represent a comprehensive answer to questions raised by a large number of patients in response to such a news story." "By posting our IRB-approved protocol on the Internet we empowered a large number of PALS outside the trial, who were likely to self-experiment with alternative therapies (13,14), to test the efficacy of a new compound with a plausible rationale."

Appendix 3.3. Extracted data by article

Ben-Pazi 2018	No name	Sound frequencies in the gamma range modulated in frequency and /or amplitude according to a fixed protocol. These sounds were embedded in background music or nature sounds according to the child's preferences.	Debby Elnatan	cerebral palsy (CP) and disabling hypertonia	Improved motor function
Berry 2019	Jacki Jacket	The jacket is a long-sleeve, soft, cotton, and Polartec® high-performance wicking fabric. The jacket allows the patient to discreetly place drainage tubes in hidden and secure inner pockets to reduce the possibility of dislodgement and pulling. Arm-length Velcro openings in the sleeves allow for easy access when patients return for follow-up appointments that require blood pressure measurement, intravenous access, injections, and/or physical exams.	Cathy McGrath is innovator according to www.patient-innovation.com	Breast cancer	
Blaser 2017	PatientsLikeMe.com				
Borentain 2019	PatientsLikeMe.com				
Bove 2013	PatientsLikeMe.com	Patient-driven innovation (PLM) used by researchers.		Multiple sclerosis	
Bove 2014	PatientsLikeMe.com				
Bove 2016	PatientsLikeMe.com				
Bradley 2016	PatientsLikeMe.com				
Brajovic 2018	PatientsLikeMe.com				
Braune 2019 DIWHY	DIYAPS; AndroidAPS	In DIYAPS, commercially available and approved medical devices such as insulin pumps and continuous glucose monitoring sensors are connected and remotely controlled by systems	Dana Lewis (DIYAPS), Adrien Tappe (Android APS), Bastian Hauck (dedoc, diabetes online community)	Diabetes T1	Glycemic control

Appendix 3.3. Extracted data by article

		using open-source algorithms to automate insulin delivery.			
Braune 2019 Real World Use	DIYAPS		Dana Lewis	Diabetes T1	
Brownstein 2009	PatientsLikeMe.com	Create a PLM OI or bone community.		Osteogenesis imperfecta (OI)	"Treatment is not standardized, often experimental, and frequently involves physical therapy, surgical interventions, and medications." "It is easy to imagine that patients with OI could have improved outcomes with increased knowledge; patients could effectively teach each other how to live better."
Brownstein 2010	PatientsLikeMe.com	Create a PLM OI or bone community.		Osteogenesis imperfecta (OI)	Members could locate other patients with similar circumstances and medical experiences and discuss the profiles, treatment reports, and general health concerns on the forum, private messages, and comments they post on one another's profiles
Castejon 2014	PatientsLikeMe.com				
Chari 2019	PatientsLikeMe.com				
Chesaniuk 2014	PatientsLikeMe.com				
Chiauzzi 2016	PatientsLikeMe.com				
Chiauzzi 2019 Digital Trespass	PatientsLikeMe.com				Not an innovation but the user need is protection of patient privacy (users of PLM and other social media).
Chiauzzi 2019 In search of	PatientsLikeMe.com				
Cleal 2019	DIYAPS		Dana Lewis	Diabetes T1	
DasMahapatra 2017	PatientsLikeMe.com				
DasMahapatra 2018	PatientsLikeMe.com				
De Bock 2019	DIYAPS	"own software algorithms, which when coupled with a continuous		Diabetes T1	glycaemic control,"demonstrated remarkable glycaemic outcomes.3–6

Appendix 3.3. Extracted data by article

		glucose monitor and insulin pump, allow the patient to 'close the loop' or automate insulin deliver"			The limitation to these data is that these individuals are highly motivated and are likely to do well; nevertheless, when compared with their own glycaemic data prior to using the DIY system, time in normal glycaemic range (4–10 mmol/L) improved by 16.4%".
De la Loge 2016	PatientsLikeMe.com	PLM used to track epilepsy patients.		Epilepsy	
De Monestrol 2018	Sweden CF coalition	The work streams aim to develop: clinical guide-lines; clinical decision support; a health information exchange; a patient support system; a national learning network and international collaboration. The group is composed of representatives from all four CF centers, the National Cystic Fibrosis Association, the CF Working Group of the Society of Medicine, the National Quality Registry Development Group, the Patient Support System Development Group, the Chair of the CF Coalition and Coalition advisors. The Group meets monthly to report back from the various work streams and to ensure progress is made towards the mission	Andreas Hager	Cystic fibrosis	stuctured follow-up and evaluation of new treatments for optimal care and best use of resources
Debong 2019	MySugr	a mobile app designed to support patients in the diabetes self-management	Fredrick Debong	Diabetes T1	Diabetes self-management
Dorsey 2016	PatientsLikeMe.com				

Appendix 3.3. Extracted data by article

dosReis 2016	PatientsLikeMe.com				
Eaneff 2017	PatientsLikeMe.com				
Eichler 2016	PatientsLikeMe.com				
Ellis 2013	PatientsLikeMe.com				
Farrington 2016	DIYAPS	patient-designed closed-loop systems		Diabetes T1	Artificial pancreas
Fergus 2017	Upsee	"approach for gait impairments in children through providing increased opportunities for walking while supporting biomechanical alignment"	Debby Elnatan	Cerebral palsy	
Frost 2008 How the social	PatientsLikeMe.com	PALS use PLM to steer investigation of possible treatment.		ALS	"Our users brought new information to us quickly as well as bringing it to themselves, acted on it, and used it to help us develop tools that more effectively show them what they want to know."
Frost 2008 Social uses of	PatientsLikeMe.com	PLM used by PALS to communicate with other PALS		ALS	[Information about other patients' real-life experiences with ALS progression and treatments.]
Frost 2009 Patients like me the case	PatientsLikeMe.com	PLM used by PALS to help with decisions about symptom management technology		ALS	"Although the value of the profile [on PLM] for patients is not yet well understood, we can infer some value exists when patients nudge one another to create them."
Frost 2011 Patient-reported outcomes	PatientsLikeMe.com				
Grande 2019 Empowering young people	Upstream dream, Genia	"Core functionality of the mPSS were operationalized within a learning collaborative associated with the Lund Pediatric Cystic Fibrosis clinical microsystem. This meant that clinicians, researchers,	Andreas Hager	Juvenile Idiopathic Arthritis	"being in the center of the decision-making process"

Appendix 3.3. Extracted data by article

		family members, and cystic fibrosis patients were involved in iterative cycles of change from inception to completion of the mPSS. Key functionalities developed within the app were inspired and optimized by patients, viewed as experts in their disease and experience of care"			
Griffiths 2015 The impact of	PatientsLikeMe.com	[Health social networks including PLM]		Various	[Users of health-related social networking sites having effect on health-care policy via connecting with others they might not otherwise encounter.]
Has 2019 Medication Adherence Prediction	PatientsLikeMe.com				
Hamed 2019 Mobility assessment using	PatientsLikeMe.com				
Heywood 2014 Straight talk with	PatientsLikeMe.com		Jamie Heywood		
Hixon 2015 Patients optimizing epilepsy	PatientsLikeMe.com				
Hng 2018 Appearence of do-it-yourself	DIYAPS	"A closed-loop system requires a processor capable of receiving CGM sensor data, and algorithms to control the rate of insulin delivery through a compatible insulin pump. This results in dynamic basal rates in response to changing glucose levels."		Diabetes T1	artificial pancreas, "reduction in psychosocial burden and improved glycaemic control"

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Hussain 2020 Part I	DIYAPS		Dana Lewis	Diabetes	
Hussain 2020 Part II	DIYAPS		Dana Lewis	Diabetes	
Jackson 2013 Feasibility of a	PatientsLikeMe.com				
James 2020 Characteristics, Symptom Severity	PatientsLikeMe.com				
Janssen 2016 A painted staircase	no name specified mentioned as "FOG with three dimensional (3D); “illusion of a 3D cue…to alleviate FOG (freezing-of-gate)”	"An example of a non-pharmaceutical intervention is the use of visual cues, e.g. stationary lines pasted at fixed distances onto the floor," or laser lines projected onto the floor, allowing patients to take externally guided steps [2]. A subgroup of patients only shows a selective improvement of FOG with three-dimensional (3D) visual cues, but not with two-dimensional (2D) cues [3	Mileha Soneji	Parkinson’s disease	mobility, "allowing patients to take externally guided steps "
Janssen 2016 Response to			Mileha Soneji	Parkinson’s disease	
Katic 2015 New approach for	PatientsLikeMe.com				
Kear 2015 Partnering with patients	PatientsLikeMe.com				
Kelman 2016 Communicating laboratory	PatientsLikeMe.com				
Kendall 2017 T1resources.uk	T1resources.uk	Self-care support	Mike Kendall	Diabetes T1	“The most powerful thing for me about managing my condition is knowing I’m not the only one and

Appendix 3.3. Extracted data by article

					T1resources.uk not only proves that, but then signposts me to information and other sites where I can get the help, support and advice I need. I'm amazed that no-one had ever thought to put together this kind of resource before, but I'm very glad it exists now."
Khan 2019 Patient survey of	PatientsLikeMe.com				
Klee 2018 An intervention by	Webdia	"Webdia is a patient-designed do-it-yourself mHealth app created by J.L.M. after diagnosis of T1DM in his 10-year-old daughter. . The mobile application was written with jQuery Mobile (JS Foundation, San Francisco, CA), an HTML5-based user interface system, and interacts with a MYSQL (Oracle Corporation, Redwood Shores, CA) database. By creating an application that communicated with a remote server, he wanted to improve his daughter's autonomy and facilitate data ex- change within the family."	Jean-Luc Mando	Diabetes T1	Monitoring "By creating an application that communicated with a remote server, he wanted to improve his daughter's autonomy and facilitate data exchange within the family."
Kontovounisios 2018 The ostom-i- alert	Ostom-i-alert	"The Ostom-iTMAlert Sensor (11 Health and Technologies Limited, Borehamwood Herts UK) is a CE-marked (Con- formité Européenne, indicating conformity with health, safety and environmental protection standards for products sold within the European Economic Area) and	Michael Seres	Stoma	Monitoring "The volume of stoma output is recorded, and alerts can be set by patients to prevent bag overflow and leakage"

Appendix 3.3. Extracted data by article

		FDA (Food and Drug Administration)-approved medical device. It uses a flexible sensor, clipped to the lower part of a stoma bag to sense when a bag is filling and to relay that data back to the patient in real time via a smartphone application"			
Lawlor 2017 Developing integrated care	unclear, referred to as "patient driven collaborative initiative"	"22q Ireland Support Group as a patient organisation, with the support of an independent research consultant, initiated dialogue with a large group of specialist clinicians from a range of health disciplines and institutions" "the establishment of a core patient-clinician working group who have collaboratively developed a comprehensive business case to seek political support, statutory and research funding for the development of the multidisciplinary networked model of integrated care".	Anne Lawlor	22q11 Deletion Syndrome	Care coordination and cost control. "Over 180 physical, functional and psychological associations have been described. The cost of care to families and to the health system is high
Lebental 2011 Patient perception	Omnipod	"One of the more recent advancements in CSII technology is the OmniPod Insulin Management System (Insulet Corp., Bedford, MA), a wireless ‘‘smart pump’’ composed of two components, the OmniPod and a Personal Diabetes Manager (PDM). The OmniPod is a disposable, self-enclosed insulin pump with automated cannula insertion that attaches directly to	John Brooks III	Diabetes T1	"smart pumps’’ offer convenience features (i.e., higher-resolution screens, custom safety alarms, remote control, integration with blood glucometer, and interface to personal computers).1–5 In addition, different customized basal programs—temporary basal, extended and combination bolus, ‘‘insulin on board,’’ and bolus calculators—allow more precision in insulin delivery"

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		the body. The handheld PDM operates the OmniPod by remote control, with customized preprogrammed insulin"			
Lee 2016 A patient-designed	DIYAPS	“The father (who is a software programmer) began developing a computer code that would enable him to access the blood glucose readings from the CGMS receiver to the computing cloud through a smartphone. With the data in the cloud, the blood glucose levels could be viewed by the parents from anywhere to provide a continuous monitoring solution"	Nightscout community	Diabetes T1	"With the data in the cloud,the blood glucose levels could be viewed bythe parents from anywhere to provide a continuous monitoringsolution"
Lee 2017 Real-world use	DIYAPS	"The Nightscout Project started when the father of a 4-yearold boy with type 1 diabetes hacked into his son’s FDA approved continuous glucose monitoring (CGM) system, uploading sensor glucose values to the Internet through an Android phone. This enabled him to access real-time sensor glucose data on personalized web-based, mobile, and wearable applications that he designed"	Nightscout community	Diabtetes T1	"continuous glucose monitoring (CGM) system, uploading sensor glucose values to the Internet through an Android phone. This enabled him to access real-time sensor glucose data"
Lewis 2015 How a DIY	Not reported	they built a “human in the loop” decision-assist system that supports a pa-tient with diabetes by re-calculating diabetes data (BG from CGM; patient-entered insulin and carbohydrate information) every 5 minutes to produce accurate predictions and	Dana Lewis, Scott Leibrand	Diabetes T1	predict and get warnings of expected BG levels

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		earlier warning of expected BG levels			
Lewis 2016 Real-world use	DIYAPS	"self-built hybrid closed loop systems by pairing small computing hardware, open source software (OpenAPS), and existing diabetes devices (continuous glucose monitors [CGMs] and older insulin pumps)".	Dana Lewis	Diabetes T1	"It has allowed patients and caregivers remarkable improvements in quality of life due to increased time in range, uninterrupted sleep, and peace of mind"
Lewis 2017 Automatic estimation	Autotune	Insulin dosing and carb data, glucose data from CGM, and pump profile settings are used to calculate expected blood glucose impact (BGI) for each glucose value. Each glucose value is then categorized as being most attributable to basal, ISF, or carb sensitivity factor (CSF=ISF/carb ratio), and used to calculate adjustments to basals, ISF, and CSF. For each hour, total BGI deviations and necessary adjustment in basal to bring deviations to 0 are calculated; 20% is applied to the previous 3 hours' basals. Median deviation for entire day's ISF-attributed data and necessary adjustment in ISF to bring the median deviation to 0 are calculated; 10% is applied. Total BGI deviations during observed carb absorption are calculated and compared to total carb intake to calculate new CSF; 10% is applied to the carb ratio.	Dana Lewis	Diabetes T1	Automatically tuning insulin pump basal rates, ISF, and carb ratios

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Lewis 2018 Detecting insulin	Autosense	Autosens analyzes each CGM data point for 24 hours, comparing observed change to expected impact from insulin. Autosens calculates the deviation for the median of the last 8 and 24 hours of CGM data points and determines the sensitivity ratio (SR) required to neutralize the median deviation.	Dana Lewis	Diabetes T1	calculate changes in insulin needs
Lewis 2018 Improvements in A1C	DIYAPS	[not in data table]	Dana Lewis	Diabetes T1	
Lewis 2018 Setting expectations	DIYAPS	Unclear	Dana Lewis	Diabetes T1	Closed loop system
Lewis 2019 Characterization of	DIYAPS, CGM data from 19 T1D individuals using a DIY closed loop APS in the OpenAPS Data Commons				
Lewis 2019 History and perspective	DIYAPS	"The first DIY closed loop system contained basic components of a mini-computer to hold the algorithm; a radio stick to communicate with the pump using its proprietary 915MHz radio protocol; a battery; and an existing insulin pump and CGM. "	Dana Lewis	Diabetes T1	Closed loop system
Li 2013 Privacy policies for	PatientsLikeMe.com	N/A	N/A	N/A	N/A
201Lindblad 2019 Sweden's learning	Sweden's CF Coalition	N/A	Andreas Hager	N/A	N/A

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Litchman 2019 Twitter analysis	DIYAPS	"OpenAPS focuses on facilitating access to artificial pancreas technology through do-it-yourself (DIY), patient-developed innovations that bridge communication between existing insulin pumps and continuous glucose monitors (CGM).1 OpenAPS and related DIY systems must be self-built, are not regulated or approved by the Food and Drug Administration, and are not managed by any commercial entity."		Diabetes T1	"to make diabetes management easier, more predictable, and less time-consuming"
Little 2013 Quantifying short-term dynamics	PatientsLikeMe.com				
Longacre 2018 Clinical adoption	Upstream dream, Genia	"Genia is a mobile iOS PSS created by a Swedish-based company Upstream Dream to optimize consensus-building in pediatric care by improving communication between patients and clinical teams, fostering disease self-management and aligning patients' goals with clinical treatment plans (see Figure 1). By doing so, Genia aims to facilitate timely, meaningful, and appropriate clinical care and ultimately to improve patients' quality of life. Through Genia,patients (or parents, depending on the patient's age) can record daily health	Andreas Hager	Cystic fibrosis	"co-ordinated care "

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		observations and symptoms between visits (eg, physical activity or gastrointestinal problems), track medications, and complete previsit reports, including treatment preferences and goals, prior to a clinical appointment. This patient-reported information allows patients to document their disease activity and preferences in the real-time between clinical visits (see Figure 2). Patient data are then integrated into the National CF Quality Registry (ie, a registry established in 1992, encompassing all 21 regional health care systems or payors in Sweden, which longitudinally follows every CF patient in Sweden) and the care flow within the clinical setting. Clinical providers—including physicians, physiotherapists, and others—are able to review patients' previsit reports as an Adobe PDF file in the CF registry prior to the clinical visit to better inform the visit and foster opportunities for shared decision making and goal setting. Patients and providers also use Genia to collaboratively document agreed upon therapeutic decisions, actionable steps, and other information derived during the clinical visit. Genia thus aims to foster patient self-			

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		management, build trusted patient-provider relationships, and increase compliance with mutually agreed upon care plans. "			
Lopez 2016 Understanding preferences for	PatientsLikeMe.com				
Ma 2015 Mental disorder recovery	PatientsLikeMe.com	[PLM social network data to track correlation between activity and mental health recovery.]		Mental health disorders	"For instance, patients may be able to discuss, via online media, their private problems without fear of prejudice or discrimination (Hsiung, 2000). Furthermore, online social media may play a complementary role to traditional mental health services and help patients understand their conditions more and take better control over their diseases and behaviors (Frost & Massagli, 2008). For example, while many treatment decisions are still made based on physicians' empirical judgments that might not have solid supporting evidence, information sharing via healthcare social media may allow patients to perceive their diseases from other patients' point of view, do their own research online, and make their own informed decisions on how to manage their diseases"
Mader 2015 Influence of	MySugr	mySugr Companion, a FDA registered and a CE-marked class I medical device, was developed to make this task more appealing. Patients can enter data on BG,	Fredrik Debong	Diabetes T1	Keeping a diabetes diary is thought to be beneficial both for diabetes self-management and therapy adjustment by health care professionals. However, a high number of patients indicate

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		meal (including images), insulin, exercise, mood			that keeping a structured paper based diabetes diary is a burden.
Marshall 2019 Do-it-yourself	DIYAPS	"An artificial pancreas provides variable automated insulin doses in response to changes in interstitial glucose and other variables, some of which require manual input."	#WeAreNotWaiting community	Diabetes T1	"optimal automated diabetes care"
McCaffrey 2018 Understanding 'Good Health	PatientsLikeMe.com				
McCaffrey 2019 Measurement of Quality	PatientsLikeMe.com				
McCarrier 2016 Concept Elicitation Within	PatientsLikeMe.com				
McNaughton 2019 Patient attitudes toward	PatientsLikeMe.com				
Melmer 2019 Glycaemic control	DIYAPS	"Do-it-yourself (DIY) artificial pancreas systems represent open source closed-loop-systems that aim to continuously and adequately meet physiologic insulin requirements in patients with diabetes. DIY systems consist of a compatible insulin pump, a continuous glucose monitoring (CGM) sensor and a third-party device holding a system- specific algorithm. The third-party device (a microcomputer or a smartphone) bridges communications between the algorithm, the insulin pump and	#WeAreNotWaiting community	Diabetes T1	"Do-it-yourself (DIY) artificial pancreas systems represent open source closed-loop-systems that aim to continuously and adequately meet physiologic insulin requirements in patients with diabetes."

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		the CGM sensor." [...] "OpenAPS uses a small microcomputer (“rig”) to bridge communications with the insulin pump and the CGM sensor. The rig also contains the OpenAPS algorithm, a single source algorithm released by the OpenAPS project team. OpenAPS released two main versions of the algorithm: Oref0, which calculates a temporary basal rate and aims to maintain blood glucose within an individual target range between meals and over- night. Oref01 adds additional features that perform meal boluses without user input. Every OpenAPS user is enabled to alter the code under their own responsibility."			
Melmer 2019 In-depth review	OpenAPS Data Commons	Many using DIY closed loop systems have chosen to donate their data to a shared, anonymized data repository called the “OpenAPS Data Commons.”	Dana Lewis, Scott Leibrand	Diabetes T1	
Moreira 2018 Measuring Relevant Information	PatientsLikeMe.com				
Nakamura 2012 Mining online social	PatientsLikeMe.com				
Nyman 2020 Characteristics and Symptom	PatientsLikeMe.com	PLM as an online community comparable in many characteristics to the general SLE		Systemic Lupus Erythematosus (SLE)	

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		community (at least the US SLE population).			
O'Brien 2019 Patient perspectives on	PatientsLikeMe.com	"Development and testing of patient-reported outcomes proceeds through the PLM Open Research Exchange, an online platform tied to the PLM research network [16]."		Various	
O'Connor 2017 The medistori	MediStori	"The MediStori has a dual purpose – it is a paper-based PHR and it is a self-management toolkit." [...] "MediStori aimed to keep all of family's information together, from birth to end-of-life; could help a patient or carer communicate relevant health information at the point of care in both primary and acute settings (a critical component for integrated care), and assist in the self-management of conditions in the home."	Olive O'Connor	Various	"The founder of this project, a patient and carer to three children with differing conditions, ascertained through lived experiences, that most acute health care settings were fragmented – many focusing on one disease at a time, meaning most often, a holistic viewpoint was not considered, thus impacting on issues such as comorbidity, medication reconciliation and disconnected health information." [...] "patients all had similar issues"
O'Donnell 2019 Evidence on	DIYAPS		Dana Lewis (DIYAPS), Adrian Tappe (Android APS), Tebbe Ubbe (Android APS), Bastian Hauck (dedoc, diabetes online community), Saskia Wolf (dedoc, diabetes online community)		
Okun 2017 Building a learning	PatientsLikeMe.com			Various	

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Okun 2018 DigitalMe: A journey	PatientsLikeMe.com				
Omer 2016 Empowered citizen	DIYAPS	"the OpenAPS project [8], which provides the instructions and blueprint of a DIY patient-built APS. "	Timothy Omer	Diabetes T1	"to keep track" of their blood sugar levels, treatments and medication calculations
Pearson 2011 Potential for electronic	PatientsLikeMe.com			Diabetes; various	
Ranney 2016 Correlation of digital	PatientsLikeMe.com				
Rifkin 2019 Treatment satisfaction and	PatientsLikeMe.com				
Riggare 2015 Patients organize	No name	Sara Riggare has created a functional prototype of a smartphone app for collecting data on drug intake and wellbeing to provide data for shared decisionmaking during the visit with the neurologist. Patients would use it for about a week before the visit	Sara Riggare	Parkinson's disease	Time with clinicians is limited, so we prioritise collecting, organising, and communicating information about our evolving health status
Rodriguez 2019 Measuring compassionate healthcare	PatientsLikeMe.com				
Rouholiman 2018 Improving health-related	Ostom-i-alert	"The Ostom-i alert sensor is a wearable device intended to make life easier for patients with ostomy bags by allowing for easier output measurements and anticipation of bag changes via a	Michael Seres	Inflammatory bowel disease	"output measurements and anticipation of bag changes "

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		Bluetooth connection to their mobile smart phone."			
Rundle 2018 PatientsLikeMe and atopic	PatientsLikeMe.com			Atopic dermatitis	
Sahama 2012 Impact of the	PatientsLikeMe.com	[Integrating several social networks, including PLM, into one open source platform.] "The result of the research enables a user to create and manage an integrated profile and share/synchronise their profiles with their social networks." / "designing a platform named Multiple Profile Manager (MPM) that enables users to create and control their own single profile, and more importantly share partial aspects of the profile with various social networks in the Onesocialweb5 (OSW) federation."		N/A	"...many web users need to manage many disparate profiles across many distributed online sources. Maintaining these profiles is cumbersome, time consuming, inefficient, and leads to lost opportunity."
Schroeder 2015 An Innovative Approach	PatientsLikeMe.com			Diabetes T1	Rapid gathering of stakeholders' research preferences.
Seres 2017 From patient to	Ostom-i-alert	"Our system is designed for both inpatients and outpatients, and consists of a detachable and reusable sensor that adheres to the outside of any pouch (Figure 1) .The sensor detects output volume and sends it in real time to your mobile phone or tablet (Figure 2) . The patient facing app allows patients to set multiple alerts about when their pouch is filling. Patients can also track their	Michael Seres	Inflammatory bowel disease	to know when stoma bag was filling up, avoid spills from stoma

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		hydration and food intake as well as their physical activity. "			
Simacek 2017 What Do Ovarian	PatientsLikeMe.com				
Simacek 2018 Patient engagement	PatientsLikeMe.com				
Simacek 2018 The Impact of	PatientsLikeMe.com				
Simacek 2019 Patient perceptions of	PatientsLikeMe.com				
Smith 2008 PatientsLikeMe: Consumer health	PatientsLikeMe.com	[As part of the structure of PLM, members contribute to] "a semi-structured alphabetical list which patients can use as an assist for future symptom reporting. It also permits comparison with symptoms reported by other people. The terms become “live” immediately, but are periodically reviewed for normalization as necessary."		ALS, MS, Parkinson's disease (PD)	[In this paper, the user need is a shared vocabulary:] "Web 2.0 privileges augmented content over semantic architecture; for example, a user-generated taxonomy called a folksonomy can be established through the construction and collaboration of user-generated index terms, or tags (such as those at Amazon.com, Flickr, Technorati, and Craigslist). The word folksonomy, coined in ironic opposition to taxonomy, was first used in 2006. Folksonomy facilitates networking of related concepts and related interests, thus creating related people; in Web 2.0, “seeing what other users are thinking about is as much a part of the site as finding what you need.”"

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Thorley 2018 Understanding How Chorea	PatientsLikeMe.com				
Tonozzi 2018 Pharmacogenetic profile and	PatientsLikeMe.com				
Tran 2014 Adaptation and validation	PatientsLikeMe.com				
Trevena 2011 PatientsLikeMe and the	PatientsLikeMe.com				
Turner 2010 Concordance between site	PatientsLikeMe.com				
Venkataraman 2014 Virtual visits for Parkinson	PatientsLikeMe.com				
White 2018 Motivations for participation	CGM in the cloud	"CGM in the Cloud is a private Facebook group that was originally created in 2014 with the purpose of sharing information about Nightscout, a do-it-yourself (DIY) mobile technology system for remotely displaying blood glucose values from a continuous glucose monitoring (CGM) system. The original computer code for Nightscout was developed by the father of a four-year-old boy with type 1 diabetes who hacked into his son's FDA-approved CGM, to upload glucose values to the Internet through an Android phone, providing real-time access	CGM in the cloud community	Diabetes T1	"continuous glucose monitoring"

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		to blood glucose data on webbased, mobile, and wearable applications. He shared his code with a community of other interested individuals which led to the creation of the Nightscout project, an informational website (http://www.nightscout.info/) with instructions and links to the open source code, as well as the formation of the CGM in the Cloud private Facebook group, permitting"			
Wicks 2008 ALS patients request	PatientsLikeMe.com				
Wicks 2009 Measuring function in	PatientsLikeMe.com	Use PLM to extend the ALSFRS-R by developing and piloting new items.		ALS	"Although a valuable instrument for clinical trials, the ALFRS-R suffers a relative lack of sensitivity in advanced stages of disease. Using a patient-centered approach we have suggested a number of additional items to add sensitivity at the floor level."
Wicks 2009 Pathological gambling amongst	PatientsLikeMe.com				
Wicks 2010 Sharing health-data	PatientsLikeMe.com			"amyotrophic lateral sclerosis [ALS], Multiple Sclerosis [MS], Parkinson's Disease, human immunodeficiency virus [HIV], fibromyalgia, and mood disorders"	"information exchange between patients"... "understand and share information about their condition"

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Wicks 2011 Accelerated clinical discovery	PatientsLikeMe.com			ALS	[Tracking self-administered experimental use of potential disease therapies.] "There are a number of benefits to systematically studying patients' self-experimentation. First, it is important to respect patients' autonomy and their decisions; helping them participate in systematic evaluations may increase scientific literacy. Second, there is an obligation to collect data on the safety of self-experimentation. Unproven treatments might have substantial safety concerns, and risks to patients may be increased without a way to report safety issues. Finally, there is the chance that something (i.e., off-label usage, a change in dosage, delivery route or combination with other treatments) might actually be shown to be efficacious, leading to further study."
Wicks 2011 Use of an	PatientsLikeMe.com	Used PLM to develop a questionnaire ("MS-TAQ, a rating scale that quantifies the barriers to adherence, side effects, and coping strategies experienced by MS patients")		MS	"A recent editorial pointed out that the "core issue of adherence" is identifying the reasons why patients have decided to be nonadherent, and that much of the literature fails to illuminate the spectrum of behavior between perfect compliance and nonadherence [25]."
Wicks 2012 Patient assessment of	PatientsLikeMe.com				
Wicks 2012 Perceived benefits	PatientsLikeMe.com	"PatientsLikeMe is a Web-based application where members explicitly choose to share detailed		Epilepsy	"information exchange between patients"

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		computable data about symptoms, treatments, and health in order to learn from the experience of others and improve their outcomes. These data are presented back to members as individual-level graphical health profiles and aggregated into reports accessible on the site. Members can discuss these data sets either within a group forum or individually through private messages. The resources on the site are designed to help members answer the question: "Given my status, what is the best outcome I can hope to achieve, and how do I get there?"'			
Wicks 2012 Reassessing received wisdom	PatientsLikeMe.com				
Wicks 2012 The multiple sclerosis	PatientsLikeMe.com	[Used PLM to recruit patients for cognitive interviews and piloting of revised MSRS]		Multiple Sclerosis	
Wicks 2014 Could digital patient	PatientsLikeMe.com			[Mentions: ALS; RA; breast cancer]	"By harnessing online patient communities it is possible to recruit a representative population of dozens or even hundreds of patients to provide qualitative and quantitative feedback at each phase of the trial recruitment process."
Wicks 2014 Data donation could	PatientsLikeMe.com			[Mentions ALS]	

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Wicks 2014 Measuring the burden	PatientsLikeMe.com				
Wicks 2014 Quality of life	PatientsLikeMe.com			Organ transplant recipients	"even after a successful transplant, patients face medical and personal challenges such as monitoring their health, adhering to medication, and coping with emotions related to their transplant such as guilt, fear, and responsibility, data that are not gathered easily—technology may provide one solution."
Wicks 2014 Subjects no more	PatientsLikeMe.com			ALS	
Wicks 2015 Preferred features of	PatientsLikeMe.com				
Wicks 2015 Spotlight: Patient centred	PatientsLikeMe.com				
Wicks 2016 Getting stem cell	PatientsLikeMe.com				
Wicks 2016 The real-world	PatientsLikeMe.com				
Wicks 2018 Patient study thyself	PatientsLikeMe.com			[Mentions: ALS; PD; diabetes]	
Wicks 2019 A Modular Health-Related	PatientsLikeMe.com				
Wild 2018 Validation of the	PatientsLikeMe.com				
Williams III 2019 The PatientsLikeMe Multiple	PatientsLikeMe.com	[Describes business model used by PLM to launch the PLM MS community.]		MS	

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Zisser 2011 Novel methodology	OmniPod and Tidepool	"The OmniPod Insulin Management System (Insulet, Bedford, MA) is currently an integral part of the Artificial Pancreas Project sponsored by the Juvenile Diabetes Research Foundation. The artificial pancreas system (APS) is a system for automating closed-loop glucose control, comprising a glucose sensor, a controller/algorithm, human user interface, and an insulin pump."	John Brooks III	Diabetes T1	Glucose control
ÅRsand 2016 Warning: the do-it-yourself	Nightscout	"the Nightscout project, the CGM in the Cloud Facebook group (20.141 members, September 2016), have brought diabetes specific solutions to patients' doors."		Diabetes	Glucose control
Oliver 2019 Open source automated	DIYAPS	"Do-It-Yourself (DIY) automated insulin delivery (AID) solutions use continuous glucose sensors, open source software running on a smartphone, and insulin pumps to create systems that deliver insulin continuously in response to changes in subcutaneous glucose. The algorithm code is available to download from freely available software development platforms such as GitHub which host non-executable code. Implementation of the systems is supported by on-line guides, peer support from expert users and developers, and		Diabetes T1	"systems that deliver insulin continuously in response to changes in subcutaneous glucose"

Appendix 3.3. Extracted data by article

		in some cases, at DIY AID meetings."			
Rivard 2020 It's not just	Nightscout	"Nightscout is a cloud-based software that enables the continuous monitoring of glucose (CGM) levels in real time for children with type 1 diabetes. The Nightscout technology was developed by CGM users with the collaboration of an online community of patients, their parents and healthcare providers, all of whom share their knowledge and time on a volunteer basis."		Diabetes T1	"Managing type 1 diabetes requires a precise combination of insulin injections and the consumption of carbohydrates. A proper monitoring of glucose levels diminishes the risks of complications related to the disease."
Shaw 2020 The DIY artificial	DIYAPS	"They consist of an insulin pump that can alter the amount of insulin delivered from moment to moment in response to the interstitial glucose measured by a continuous glucose monitor"		Diabetes T1	
Shepard 2020 User and healthcare	DIYAPS	"open-source APS technology through patient-built systems, also known as "do-it-yourself" artificial pancreas systems"		Diabetes T1	"the development of such sophisticated technology and the associated rigorous clinical validation and regulatory process aimed at demonstrating safety and efficacy are lengthy and delay commercial availability. Frustrations about the lack of access to these novel devices"
Torous 2017 Patient-driven innovation	No name	"he needed data to measure the number of hallucinations experienced per day during the time he was changing his medication."	Spencer Roux	Schizophrenia	"Spencer wanted to be able to quantify the effects of this new medication."

Appendix 3.3. Extracted data by article

Vaidyam 2020 Patient innovation	No name	"The Nordic Thingy prototyping platform has numerous sensors not available in a smartphone that are able to achieve a high fidelity of measurement recording. The device was preloaded with a long-term evolution (LTE) data plan. The sensors include the following: LTE, Bluetooth, Wi-Fi, near-field communication (NFC), button, temperature, humidity, air quality, air pressure, ambient color, ambient light, high-g accelerometer, low-power accelerometer, global position system (GPS), digital microphone, radio frequency (RF) frequency (RF) antenna, barometer, altitude, 9-axis motion tracker. It also has a multicolor light emitting diode (LED) and digital buzzer (a low-quality speaker) for responding to the user if necessary."	Spencer Roux	Schizophrenia	"Seeking to constantly improve his condition and curious about the impact of various environmental aspects on his mental health, SR sought to quantify such environmental aspects."
Zabinsky 2020 Do-it-yourself	DIYAPS			Diabetes T1	
Burnside 2020 Do-it-yourself	DIY AID (Do-it-yourself automated insulin delivery)	This article has a broad discussion of DIY APS systems and their potential. "The advent of capable smartphones and accurate continuous glucose monitoring systems has allowed motivated individuals with type 1 diabetes to develop their own software algorithms which allow these devices (including insulin pumps) to “talk” to one another,	Mentions Dana Lewis as initial Artificial Pancreas System (APS) innovator who launched Open Artificial Pancreas System (OpenAPS) movement; article discusses extension of DIY automated	Diabetes T1	Continuous glucose monitoring and regulation of insulin delivery; "Such a system has the potential to reduce the cognitive burden associated with laborious diabetes tasks, hence improving quality of life for those living with type 1 diabetes."

Appendix 3.3. Extracted data by article

		fashioning the so-called DIY artificial pancreas system (APS) or “closed loop” system."	insulin delivery (AID) technology to include AI and ML.		
Crabtree 2019 DIY artificial pancreas	DIYAPS (artificial pancreas systems)	"do-it-yourself artificial pancreas system (DIY APS) describes the automated insulin delivery closed-loop systems developed by the diabetes community, often referred to as ‘OpenAPS’, although this term actually only refers to one of many specific types of DIY APS."	OpenAPS: Mentions Ben West, Scott Leibrand and Dana Lewis, as innovators of original APS; Loop: Nate Racklyeft and Pete Schwamb; Android APS: Milos Kozak and Adrian Tappe	Diabetes T1	Continuous glucose monitoring and regulation of insulin delivery; "Managing type 1 diabetes on a daily basis is a labour-intensive process; it has been estimated that using DIY APS can save up to one day per month in time." "Users of DIY APS report the single biggest improvement is the ability to have an uninterrupted night’s sleep and to wake up with the glucose level in range.4,6 Users of the system have describe it as ‘life changing’;”
Dowling 2020 Do-it-yourself closed-loop	DIY closed-loop systems for managing type 1 diabetes	"A DIY closed-loop involves the use of continuous glucose monitoring (CGM; or flash glucose monitoring with the addition of hardware that allows conversion to real-time CGM), an algorithm that calculates insulin doses, a communication device and an insulin pump. Together, these systems automatically adjust basal rates and bolus doses in response to CGM values. In simple terms, as blood glucose rises, the system automatically delivers more insulin, and as it drops, the system delivers less."		Diabetes T1	Continuous glucose monitoring and regulation of insulin delivery; "Diabetes technology systems can be seen as an attractive solution to the relentlessness of th[e] day-to-day burden [of diabetes management]."
Jennings 2020 Do-It-Yourself Artificial Pancreas	DIYAPS	"DIY APS use open-source software to automate insulin delivery (eg, OpenAPS,10 AndroidAPS,11 or Loop12). Each		Diabetes T1	"The use of complex technologies such as CSII and CGM can offer improved metabolic benefits and QoL for those with T1D.38 However, the training

Appendix 3.3. Extracted data by article

		of these systems uses algorithms to continually collect and analyze data on glucose, insulin, and food to predict future glucose levels. Commands are issued via the insulin pump to adjust insulin delivery with reference to the programmed glucose target levels and other personalized settings. This information is continuously fed back into the system where it is analyzed to make future adjustments."			required, time taken for continuous self-management, and decision making with these technologies can also cause a burden that forms a barrier to achieving favorable metabolic and psychological outcomes.38 Artificial pancreas systems that can constantly adapt to changing physiology and activities for PWD offer great advantages." "Respondents' motivations for using DIY APS were to achieve better overall glycemic control, to reduce short- and long-term complications, to alleviate the burden of diabetes, and to improve sleep for PWD and their caregivers."
Kublin 2020 The Nightscout system	Nightscout	"Nightscout is a non-commercial do-it-yourself (DIY) system…operates on open-source software, which means it can be continuously updated. The idea of the project is to give authorised users online access to data on continuous monitoring of glucose in interstitial fluid."		Diabetes T1	[CGM (continuous glucose monitoring) systems] "allow patients with diabetes easier and continuous access to real-time data on their glucose levels." Nightscout helps with CGM in younger patients: "In addition, children without parental control are more vulnerable to pressure from their social environment and are more inclined to ignore therapeutic recommendations. The Nightscout project was initiated to facilitate glucose monitoring by caregivers of people with diabetes mellitus [7]."
Lemieux 2020 Do-It-Yourself Artificial Pancreas	DIYAPS	"Do-it-yourself artificial pancreas systems (DIY APS) use open-source software to deliver insulin in an automated fashion."		Diabetes T1	"Despite considerable effort, few pregnant women with type 1 diabetes achieve the tight glycemic control required in pregnancy."

Appendix 3.3. Extracted data by article

Litchman 2020 Patient-Driven Diabetes Technologies	OpenAPS (and other DIY systems such as Nightscout)	"Nightscout was developed to provide remote monitoring of CGMs, but has expanded to include a series of real-time monitoring and retrospective data analysis tools that can display data from multiple kinds and brands of diabetes devices.5 OpenAPS is a movement around facilitating access to basic artificial pancreas (APS) technology, primarily driven by the development of an open source “do-it-yourself” (DIY) version of a hybrid closed loop, using existing pumps, CGM, and off the shelf hardware alongside an open-source community-developed algorithm to automate insulin dosing"	Dana Lewis (originator of OpenAPS) is an author	Diabetes T1	"Therefore, out of necessity, patients experiment with different doses of insulin or bolusing techniques (ie, extended boluses or “super boluses”) to effectively manage their diabetes."
Murray 2020 Health Care Provider	"Do-it-yourself automated insulin delivery systems (eg, OpenAPS, AndroidAPS, Loop, and Omnipod Loop)"	"Do-it-yourself automated insulin delivery systems (eg, OpenAPS, AndroidAPS, Loop, and Omnipod Loop) are open source software programs available through a coding process that can be downloaded or “built” as an application by the patient (using instructions readily available online). Once built, these applications can be deployed for use on one’s phone or minicomputer, with the end result of automating an insulin pump’s temporary basal rates (eg, Medtronic Minimed or Omnipod pumps). This automation of		Diabetes T1	[Reduces T1D care burden:] "an effective, affordable, and customizable solution for diabetes management"

Appendix 3.3. Extracted data by article

		temporary basal rates is guided by glucose rise and fall."			
Ng 2020 Evolution of Do-It-Yurself	Nightscout	"It started in 2013 when the father of a four-year-old child with newly diagnosed type 1 diabetes (T1D) recognized a need to monitor his child's blood glucose (BG) levels in real time while away at school.1 He developed computer code that would send his child's BG readings from a Food and Drug Administration (FDA)-approved continuous glucose monitoring (CGM) system to the computing cloud so that he could see the glucose data remotely on a laptop, mobile phone, or smartwatch. He later shared this code with other patients and caregivers in the T1D community."		Diabetes T1	(CGM (continuous glucose monitoring) by caregiver]: "need to monitor his child's blood glucose (BG) levels in real time while away at school"

Appendix 3, Categorization of extracted data

Data item	Categorization	Explanations	Examples
Journal	General medicine	Journals with a broad scope that publish research related to general medicine, oncology and neurology. This category also includes biotechnology and pharmaceutical science.	Nat Biotechnol Chron Respir Dis Clin Chem Med J Aust Nat Med Am J Bioeth Bmj-British Medical Journal PeerJ JAMA, Journal of the American Medical Association Journal of Neurology BMC Medicine Journal of Neurology The Lancet Biomedical Engineering Online Dermatol Online J Internal medicine journal Plos One BMC Med
	Specialized medicine	Journals with a scope on specific diagnoses, i.e. diabetes	Epilepsy & Behavior Clin Orthop Relat Res Diabetes Technology & Therapeutics Journal of Diabetes Science and Technology Diabetes The American Journal of Gastroenterology JMIR Ment Health

Appendix 3, Categorization of extracted data

		Pediatric Physical Therapy American Journal of Gastroenterology Pediatric Pulmonology JMIR Pediatrics and Parenting Techniques in Coloproctology Practical Diabetes Diabetes Therapy Diabetes, Obesity and Metabolism Breast Cancer Research and Treatment Pediatric Endocrinology Diabetes and Metabolism Canadian Journal of Diabetes Diabetic Medicine
Process related	Journals with a focus on process in research and healthcare, i.e. protocols, frameworks, methods.	AMIA Annu Symp Proc Journal of Communication in Healthcare Trials Policy Internet International journal of integrated care Learn Health Syst JMIR Research protocols Int J Med Inform BMJ Qual Saf
Digital health	Journals with a focus on digital healthcare, including advances in technology in medicine and m-health	Journal of Medical Internet Research Stud Health Technol Inform J Am Med Inform Assoc Interactive Journal of Medical Research JMIR Mhealth & Uhealth NPJ Digit Med

Appendix 3, Categorization of extracted data

			Jmir Mhealth and Uhealth
	Patient oriented	Journals that have patients in focus, i.e. *The Patient,* that cover development, evaluation and implementation of therapies, technologies, and innovations that will enhance the patient experience.	The Patient
Country	Europe North America South America Asia Oceania Africa	Country of first author's affiliation	
Publication type	Original research	Articles published as "original research", "research article" etc.	Grande SW, Longacre MR, Palmblad K, Montan MV, Berquist RP, Hager A, et al. Empowering Young People Living With Juvenile Idiopathic Arthritis to Better Communicate With Families and Care Teams: Content Analysis of Semistructured Interviews. JMIR mHealth and uHealth. 2019;7(2):e10401
	Short report	Articles published as "Brief report" or "short paper"	Braune K, O'Donnell S, Cleal B, Lewis DM, Tappe A, Hauck B, et al. DIWHY: Factors Influencing Motivation, Barriers, and Duration of DIY Artificial Pancreas System Use among Real-World Users. Diabetes.68:3

Appendix 3, Categorization of extracted data

Protocol	Articles presenting a study protocol	Rouholiman D, Gamble JG, Dobrota SD, Encisco EM, Shah AG, Grajales FJ, et al. Improving Health-Related Quality of Life of Patients With an Ostomy Using a Novel Digital Wearable Device: Protocol for a Pilot Study. JMIR research protocols. 2018;7(3)
Letter to editor/ commentary	Text published as “letter to the editor”, “commentary”, “personal view”. Not peer-reviewed research.	Riggare S, Unruh KT. Patients organise and train doctors to provide better care. BMJ. 2015;351:h6318
Conference abstract	Published conference abstracts.	Lindblad A, Hedborg A, Elidottir H, de Monestrol I, Hjelte L, Ericson P, et al. SWEDEN'S LEARNING HEALTH SYSTEM APPROACH TO NEW THERAPIES: NINE MONTHS WITH LUMACAFTOR/IVACAFTOR. Pediatr Pulmonol. 2019;54:S444-S
Editorial	Published text written by person having an editorial role at a journal. This was sometimes patients.	deBock M. The 'do it yourself' type 1 diabetes dilemma for medical practitioners. Internal Medicine Journal. 2019;49(5):559-61
Review	We included review-articles that published original data not published elsewhere.	Kublin O, Stepien M. Effect of using the nightscout system on metabolic control, safety, and incidence of complications in patients with diabetes mellitus. Wiadomosci Lekarskie. 2020;73(7):1427-33.

Appendix 3, Categorization of extracted data

	Special section dedicated to patients	special section "in my own voice" and "personal perspective"	Ahrens S. Opening (and Swallowing) A Can of Worms to Treat My Crohn's Disease. The American journal of gastroenterology.111(7):918-20.
Study aim	Describe the innovation	Articles with an aim to describe the innovation in some way	Ellis L, Showell C, Turner P. Social media and patient self-management: not all sites are created equal. Studies in health technology and informatics. 2013;183:291-5.
	Describe development of innovation	Articles with an aim to describe some part of development of the innovation	Jennings P, Hussain S. Do-It-Yourself Artificial Pancreas Systems: A Review of the Emerging Evidence and Insights for Healthcare Professionals. Journal of Diabetes Science & Technology. 2020;14(5):868-77.
	Describe users	Articles that aim to describe characteristics of persons who use the innovations	Hng TM, Burren D. Appearance of Do-It-Yourself closed-loop systems to manage type 1 diabetes. Internal Medicine Journal.48(11):1400-4.
	Describe how users perceive the innovations	Articles that aim to describe how users perceive the innovations	Lebenthal Y. Patient Perceptions of Using the OmniPod System Compared with Conventional Insulin Pumps in Young Adults with Type 1 Diabetes. Diabetes technology & therapeutics. 2012;14(5):411-7.
	Test effect/impact of innovations	Articles that aim to test the effect and/or impact of patient-driven innovations	Lemieux P, Yamamoto J, Donovan L. 44 - Do-It-Yourself Artificial Pancreas System Use in Pregnancy in a Real-World Setting: A Case Report...Virtual Diabetes Canada/CSEM

Appendix 3, Categorization of extracted data

			Professional Conference, October 28-30, 2020. Canadian Journal of Diabetes. 2020;44(7):S20-S.
	Describe/discuss ethical issues	Articles that describe and/or discuss ethical issues related to patient-driven innovations	Crabtree TSJ, McLay A, Wilmot EG. DIY artificial pancreas systems: here to stay? Practical Diabetes. 2019;36(2):63-8.
	Describe/discuss policy change	Articles that describe and/or discuss ethical issues related to patient-driven innovations	Murray JA, Clayton MF, Litchman ML. Health Care Provider Knowledge and Perceptions of FDA-Approved and Do-It-Yourself Automated Insulin Delivery. Journal of Diabetes Science & Technology. 2020;14(6):1017-21.
Study design (categorized using a classification by Ranganathan et al. 2018)	Descriptive	Studies with a qualitative design or studies that describe characteristics of a sample but relationships between variables are not analyzed, e.g. case reports, case series, descriptive cross-sectional surveys (1)	Shepard JA, Breton M, Nimri R, Roberts JTF, Street T, Klonoff D, et al. User and Healthcare Professional Perspectives on Do-It-Yourself Artificial Pancreas Systems: A Need for Guidelines. Journal of Diabetes Science & Technology. 2020:1932296820957728.
	Observational	Studies that analyze relationships between variables but exposure is not determined, or the exposure is naturally determined (1)	ZABINSKY J, HOWELL H, GHEZAVATI A, LEWIS DM, NGUYEN A, WONG JC. 988-P: Do-It-Yourself Artificial Pancreas Systems for Type 1 Diabetes Reduce Hyperglycemia without Increasing Hypoglycemia. Am Diabetes Assoc; 2020.
	Experimental	Studies that analyze relationships between variables with a pre-determined exposure that the researcher actively distribute to the study population (1)	Berry DL, Blonquist TM, Halpenny B, Hong F, Morrison-Ma SC, McCullough MC, et al. The Jacki Jacket after mastectomy with reconstruction: a randomized pilot study. Breast Cancer Research and Treatment. 2020;179(2):377-85.

Appendix 3, Categorization of extracted data

	No design	Empirical data not presented in the article	Seres M. From Patient to Patient-Entrepreneur: Development of an Ostomy Bag Sensor. The American journal of gastroenterology.113(1):8-10.
Sample size	1-5 5-25 26-100 101-200 201-500 501-1000 <1001		
Medical condition	Cancer	Breast cancer	Berry DL, Blonquist TM, Halpenny B, Hong F, Morrison-Ma SC, McCullough MC, et al. The Jacki Jacket after mastectomy with reconstruction: a randomized pilot study. Breast Cancer Research and Treatment. 2020;179(2):377-85.
	Diabetes		Lewis DM, Leibr, S, Street TJ, Phatak SS. Detecting Insulin Sensitivity Changes for Individuals with Type 1 Diabetes. Diabetes.67:2.
	Disabilities	Cerebral pares	Ardolino E, Flores M, Manella K. Gross Motor Outcomes After Dynamic Weight-Bearing in 2 Children With Trunk Hypotonia: A Case Series. Pediatric Physical Therapy.29(4):360-4.
	Gastrointestinal diseases	Crohn’s Disease	Ahrens S. Opening (and Swallowing) A Can of Worms to Treat My Crohn's Disease. The American journal of gastroenterology.111(7):918-20.

Appendix 3, Categorization of extracted data

Mental illness	Schizofrenia	Vaidyam A, Roux S, Torous J. Patient Innovation in Investigating the Effects of Environmental Pollution in Schizophrenia: Case Report of Digital Phenotyping Beyond Apps. JMIR mental health. 2020;7(8):e19778.
Multiple conditions		Chiauzzi E, DasMahapatra P, Cochin E, Bunce M, Khoury R, Dave P. Factors in Patient Empowerment: A Survey of an Online Patient Research Network. Patient-Patient Centered Outcomes Research.9(6):511-23.
Parkinson's disease		Riggare S, Unruh KT. PERSONAL VIEW Patients organise and train doctors to provide better care. BMJ-British Medical Journal.351:2.
Rare diseases	22q11 deletion syndrome Cystic Fibrosis	Lawlor A, Kerin L, Orr D, Leahy R, Crotty F, Kelleher S, et al. Developing integrated care in the context of rare chromosomal conditions: 22q11 Deletion Syndrome; A parent/clinician collaboration. International Journal of Integrated Care (IJIC). 2017;17:1-2.

1. Ranganathan P, Aggarwal R. Study designs: Part 1 - An overview and classification. Perspectives in clinical research. 2018;9(4):184-6.

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